Influence of socioeconomic status on healthcare communication involving head and neck cancer patients

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Abstract

Socioeconomic status (SES) is defined as an individual's access to resources as well as their position within society in comparison to others. It has been linked to inequalities in health, as well as differences in doctor-patient communication across a range of patient groups. However most of the research in this area focuses on doctor behaviours, as opposed to patient behaviours. Therefore this thesis presents a series of studies aimed at exploring how and why SES affects doctor-patient communication in head and neck oncology review appointments, with a particular focus on patient participation behaviours.

The study presented in chapter 5 examined whether area-level deprivation influenced patients' raising of concerns using the Patient Concerns Inventory (PCI), a question-prompt list. Results showed that there were no significant differences, but lower SES patients had worse quality of life.

Study 1, the systematic mapping review (chapter 7), looked at studies on patient participation behaviours and SES, identifying patterns in the characteristics of included studies such as the measures of SES used. The review concluded that relatively little research had looked at occupation, area-level deprivation, raising concerns, and rapport building. Head and neck cancer settings in the UK had also been under-researched.

Given that the study presented in chapter 5 simply looked at PCI responses and not the consultations themselves, Study 2 (chapter 8) analysed head and neck cancer follow-up consultation recordings, to examine area-level deprivation and raising of concerns. No significant differences were found, however more deprived patients had shorter consultations, possibly indicating a difference in the amount of relational talk.

This would not have been picked up by the measure which I used to analyse the consultations, therefore the final study (chapter 9) qualitatively explored how and why SES influenced consultant-patient communication in head and neck clinics across a range of SES measures and communication behaviours, including relational talk. Findings suggest that interactions differed in terms of relational talk, active or passive participation, and patients' preferences, with differences only occurring by individual-level SES variables.

This thesis significantly contributes to the literature in this area by exploring a wide range of SES variables and patient behaviours in a UK based head and neck cancer setting, using a mixed-methods approach. Furthermore, my findings challenge the commonly held assumption that low SES patients want to actively participate in their consultations, but cannot. It seems that such patients are satisfied with a more passive role in their care. It is possible that the PCI may be an effective way of helping low SES patients raise concerns without taking an active role in the consultation, thus potentially reducing inequalities in communication and health. This may explain the lack of significant differences in raising concerns found in both chapter 5 and Study 2, however more studies (including randomised controlled trials) are needed on use of the PCI.

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Chapter 1: Introduction

1.1 Introduction

This chapter provides a summary of the literature which has informed the design of the studies which this thesis consists of. It also provides an overview of the thesis structure and the research questions which have been set over the course of the PhD.

1.2 Background

Head and neck cancer can be an extremely debilitating condition, affecting not only the patient's health but many other areas of their life. Patients have described embarrassment eating in front of others due to problems with feeding, reluctance to leave the house or see loved ones due to disfigurement, frustration at trying to make themselves understood when speaking, fear of the cancer returning after treatment has ended, and many more (Flexen, Ghazali, Lowe, & Rogers, 2012; Ghazali et al., 2013; S. N. Rogers, 2010; S. N. Rogers, Hogg, et al., 2015; S. N. Rogers, Scott, Lowe, Ozakinci, & Humphris, 2010), as will be outlined in more detail in chapter 2.

One important contact for these patients is their consultant at the head and neck cancer review clinic. They regularly have appointments with this consultant (or occasionally a registrar) who examines them for signs of the cancer returning as well as any other related issues, and to give them a chance to express any concerns. However whether they express any concerns, and how the consultant responds to these, varies, as is outlined in chapter 4.

Previous research has found that a variety of factors can influence doctor-patient communication, in terms of both patient communication behaviours and doctor communication behaviours. One such factor is patient socioeconomic status (SES) (see chapter 4) (Verlinde, De Laender, De Maesschalck, Deveugele, & Willems,

2012; S. Willems, De Maesschalck, Deveugele, Derese, & De Maeseneer, 2005). When taken in the context that low SES individuals are more likely to develop head and neck cancer (Conway et al., 2010), as well as experience poorer quality of life and survival rates following treatment (see section 3.3.1) (Rylands, Lowe, & Rogers, 2016a, 2016b), it seems that low SES head and neck cancer patients may be at a significant disadvantage when it comes to their review appointments.

As outlined in chapter 7, there are a lack of studies on patient participation behaviours in consultations and SES involving head and neck cancer patients in the UK. Much of the present literature is conducted in the USA, focusing mainly on education and involvement in decision-making, while other SES measures and patient participation behaviours are relatively neglected.

Liverpool and Merseyside are some of the most deprived areas in the UK according to the findings of the 2015 Indices of Multiple Deprivation (IMD) (*The English Indices of Deprivation 2015*, 2015). Conducting these studies in the Merseyside area offered an important insight into the perspectives of a disadvantaged population, and will hopefully contribute to important improvements in their quality of life.

1.3 Thesis outline

The overall aim of this PhD was to gather more data on how SES affects doctor-patient communication in head and neck cancer clinics and why these SES differences might exist, with a particular focus on patient participation behaviours. Each study is presented in a separate chapter with sections on the rationale for the study, methods, results, and discussion. The findings of each study have informed the design of subsequent studies presented in this thesis.

Chapters 2 to 5 consist of my review of the literature, with each chapter representing a different area of literature. Chapter 2 provides an overview of what head and neck cancer is, the symptoms associated with the condition, groups commonly affected by the condition, risk factors, treatment options, and outcomes. Chapter 3 discusses the definition of SES, ways of measuring it, and some health inequalities specifically related to SES. Chapter 4 explores what constitutes doctor-patient communication, as well as the various factors which can influence communication, what is classed as good communication and the benefits of it, the various measures which can be employed to study communication in clinical settings, and finally some interventions which have been used to try and improve doctor-patient communication. Finally chapter 5 focuses specifically on a paper which I was involved in writing and interpreting the findings, which examined the relationship between area-level deprivation and head and neck cancer patients' use of a question-prompt list.

Chapter 6 outlines the aims and research questions of each of the three studies presented in the PhD.

Chapter 7 (study 1) is a systematic mapping review which summarises the characteristics of studies which have reported the effect of SES on patient participation behaviours. Such characteristics include measure of SES used, patient participation behaviour studied, country the study was conducted in, population studied, and year of publication. This maps the literature which has already been conducted in the field of patient participation, and identifies gaps which need to be addressed.

Chapter 8 (study 2) is a quantitative study which examines if there is an association between area-level deprivation and doctor-patient communication in recordings of head and neck cancer clinic consultations.

Chapter 9 (study 3) is a qualitative study which utilises consultation recordings, observations, and patient interviews, as well as a range of SES measures. This is in order to gain a more in depth understanding of how and why SES might influence doctor-patient communication in head and neck cancer clinics.

Chapter 10 concludes this thesis by answering the research questions (see section 1.3.1) and drawing together the evidence from the three studies. There is a section which reflects on some limitations of the studies conducted, and the chapter concludes with a few recommendations for practice and future research.

1.3.1 Research questions

Over the course of the PhD three research questions have been set:

- What research has been done to explore why does the tendency to and desire for patient participation behaviours in healthcare consultations with doctors vary according to SES and what aspects of SES have been explored?
- Does the number of concerns raised during head and neck cancer consultations significantly differ depending on the patient's IMD status?
- How and why does the doctor-patient interaction differ by patient SES in head and neck cancer consultations?

1.4 Conclusion

Therefore this thesis contributes significant knowledge to the field of doctor-patient communication, specifically the under-researched area of SES and patient participation within head and neck cancer clinics in the UK. Importantly, it looks in

depth at the complexities of SES and how it affects patients' relationships with their consultant.

Chapter 2: Head and neck cancer

2.1 Description and incidence of head and neck cancer

Head and neck cancer can be a chronic life-limiting illness which affects various areas of the head and neck, such as the mouth (oral), throat (oropharyngeal) and voicebox (larynx) (Braakhuis, Leemans, & Visser, 2014) (ICD Cancer of the Head and Neck: ICD-10 C00-C14, C30-C32). Head and neck cancer is the sixth most common cancer in the world, and typically these cases tend to be squamous cell carcinomas of the head and neck, representing more than 90% of cases (Vigneswaran & Williams, 2014).

The most common types of head and neck cancer are oral, oropharyngeal and laryngeal (Braakhuis et al., 2014; Guntinas-Lichius et al., 2014). Common symptoms of head and neck cancer include lumps or ulcers in the head and neck area which don't heal, sore throat, difficulty swallowing, and changes to the voice (such as hoarseness), although these may differ depending on the specific site and size of the tumour. Cancers at different sites present as different symptoms for example oral cancer typically presents as mouth ulcers, oropharyngeal cancer as a sore throat or neck lump (lymph node), and laryngeal cancer as a hoarse voice. Pain is often a common symptom for all head and neck cancers. Head and neck cancer is more common in men than women, with individuals over 60 years of age being more likely to develop a head and neck cancer (McCarthy, Field, Rajlawat, Field, & Marcus, 2015), although this pattern is changing due to the prevalence of Human Papilloma Virus (HPV) infection.

The tumour, node, metastasis (TNM) staging system is used by clinicians to classify tumours of the head and neck based on findings from physical exams, imaging techniques, intraoperative investigations, and pathology testing. This records

information on characteristics of the tumour at the primary site, degree of regional lymph node involvement, and whether there are distant metastases. This is then used to assign the patient to a stage ranging from I to IV, with Stage III and IV cancers being classed as advanced. This information facilitates the management and monitoring of the patient's condition and prognosis (Deschler & Day, 2008).

Most head and neck cancers are referred and seen through the two week suspected cancer referral and pathway, however a recent study conducted in Scotland found that between January 2010 and December 2014, 7% of all head and neck cancer cases diagnosed in the region were emergency presentations (Bannister, Vallamkondu, & Wah-See, 2016). All of these emergency cases were advanced stage cancer and the most common type of head and neck cancer in this group was oropharyngeal. Survival was significantly shorter for emergency patients than non-emergency patients, and hospital admissions for complications of chemoradiotherapy were significantly higher in emergency than non-emergency patients (Bannister et al., 2016). This suggests that patients diagnosed with head and neck cancer via an emergency pathway tend to be at a more advanced stage, have poorer survival rates, and more severe treatment complications, emphasising the importance of early detection and treatment.

2.2 Risk factors

The main risk factors for development of head and neck cancer are smoking and alcohol consumption. A pooled analysis of data from 15 case-control studies across the world found an increased risk of head and neck cancer for cigarette smoking and alcohol consumption. This risk was even higher for those who had been smokers for a longer period of time, smoked more frequently and reported a higher number of pack years. However the increased risk was only found for high frequency alcohol

consumption in oropharyngeal and laryngeal cancers (Hashibe et al., 2007). Another case-control study conducted in the United States found similar results, but also an even higher risk of oropharyngeal cancer for individuals who both smoked and consumed alcohol. These risks were multiplicative. In addition, risk significantly decreased when an individual stopped smoking (Blot et al., 1988). An interactive effect of smoking and alcohol consumption on increased risk for head and neck cancer was also found in a pooled analysis of 17 case-control studies worldwide (Hashibe et al., 2009). Furthermore, non-smoking use of tobacco is also linked to an increased risk of oral cancer (Boffetta, Hecht, Gray, Gupta, & Straif, 2008).

Oral human papilloma virus (HPV) infection has also been identified as a risk factor for developing oropharyngeal cancer. Most cases are a result of oral sex, and patients with HPV related head and neck cancer tend to be younger at less than 60 years of age, higher socioeconomic status and have better survival rates (Peterson et al., 2017; Taberna et al., 2017). A study conducted in the US using an all-male sample found that patients diagnosed with HPV-related head and neck squamous cell carcinoma were more likely to live in areas with higher education levels, household income and private health insurance (Peterson et al., 2017).

2.3 Treatment

The mainstay of treatment for head and neck cancers are surgery, radiotherapy, chemotherapy, or some combination of the three. Each treatment has its own side-effects and potential impact on the patient's quality of life (Nutting, 2016). Decisions about treatment are influenced by factors such as cancer site and stage, patient age, and comorbidity. These are usually discussed by a multidisciplinary team of healthcare professionals involved in the patient's care. This is discussed with the patient and their views are taken into account when making a decision, however

patients are not always involved to the same degree in such decisions about their healthcare.

2.3.1 Surgery

There are various types of surgery used in the treatment of head and neck cancer. This can involve tumour ablation, neck dissection, and reconstructive techniques, although this will also depend on the site of the cancer, the stage and whether it has spread.

Small oral or throat cancers can sometimes be treated using transoral laser surgery. This is where the operation is done through the patient's open mouth and the cancer is removed using a laser. However larger cancers may require an external incision, leaving behind some visible scarring. Neck dissection is used to treat known neck metastasis (N positive necks) or in a prophylactic manner in N negative necks in cases where clinical and radiological assessment might have missed an early metastasis. This involves removing the affected lymph nodes, and can impact shoulder movement or some of the facial muscles, such as the accessory nerve or marginal mandibular nerve.

Laryngeal cancers may be treated by cordectomy (partial or complete removal of the vocal chords) or laryngectomy (partial or complete removal of the larynx), depending on the site and stage of the cancer. Both of these surgeries impact speech to varying degrees.

Reconstructive surgery may be undertaken if tissue is removed which is crucial for speech, swallowing or appearance. Tissue from other parts of the body may be used to replace removed tissue, or if a patient's jawbone has been removed this is usually

replaced with bone from the lower leg. In cases where a cheek bone or palate is removed, a prosthesis is usually offered to the patient to replace the removed tissue.

2.3.2 Radiotherapy

Radiotherapy involves the use of high-energy radiation over the course of several weeks to stop the growth of tumours or even shrink them. Head and neck cancer is usually treated using external beam radiotherapy, however for some cases internal radiotherapy (brachytherapy) is used. If the cancer is an early stage then radiotherapy may be used as a primary treatment, however for more advanced cancers radiotherapy might be used in combination with surgery, chemotherapy, or both. Chemotherapy with radiotherapy is the primary treatment option for advanced stage oropharyngeal cancer, however patients have to be under 70 years of age for cisplatin based chemotherapy. Early oropharyngeal cancer is usually either chemotherapy with radiotherapy or transoral laser resection, neck dissection and post-operative radiotherapy. Oral cancer is usually treated using surgery and for more advanced disease surgery is followed by radiotherapy or chemotherapy with radiotherapy. Radiotherapy can be used to reduce the risk of recurrence following surgery, and it can also be used for only about two weeks in palliative cases to shrink tumours which might be causing breathing problems, swallowing problems, or pain.

There are a number of acute and chronic side-effects associated with radiotherapy including oral mucositis (sore mouth and throat), soreness in the affected area, dry mouth, loss of taste, hoarse voice, fatigue, bad breath, and sticky saliva. This can impact what food and drink the patient is able to consume without discomfort, increase the risk of infection in the mouth, cause ulceration in the mouth, result in the necessity of a nasogastric tube or PEG tube, make wearing dentures uncomfortable, and increase the risk of tooth decay. Weight loss can also occur due

to these side-effects, and some hair loss is common as well. Side-effects are more severe when radiotherapy is combined with chemotherapy, however sometimes Intensity-Modulated Radiotherapy is used instead of standard radiotherapy in an attempt to reduce the number of side-effects experienced.

2.3.3 Chemotherapy

Chemotherapy is the use of cytotoxic drugs to destroy cancer cells. These drugs typically target rapidly dividing cells in the body. This applies to cancer cells, however it also applies to certain healthy cells such as those which are responsible for hair growth, those which line the mouth, and those which are present in the bone marrow.

Cancer drugs are usually administered orally or intravenously. The drugs which are most commonly used to treat head and neck cancer are cisplatin, carboplatin, docetaxel, capecitabine, fluorouracil, and gemcitabine. Chemotherapy can be used alone, however it is usually used in conjunction with surgery, radiotherapy or both. Usually if it is used with surgery, chemotherapy is administered afterwards to destroy any remaining cancer cells. In addition to being used in a curative capacity, chemotherapy can also be used palliatively to reduce symptoms and improve the patient's quality of life.

There are several side effects associated with chemotherapy, including hair loss, nausea and vomiting, sore mouth and throat, hearing loss, kidney problems, rashes, fatigue, peripheral neuropathy, and loss of appetite. Chemotherapy can also lead to early menopause in women, infertility, the development of certain types of cancer later in life, and later heart or lung problems. Patients can also develop anticipatory nausea and vomiting, in which these symptoms occur before a chemotherapy session

has started. This usually develops after a few chemotherapy sessions have been completed, via behavioural conditioning. It can be associated with a particular type of food, a hospital setting, or even a certain smell. In some cases a novel tasting ice cream is given to patients before their chemotherapy session, so that they develop nausea in association with that food rather than a food which they eat regularly.

Patients can cope with the different side effects in a number of ways. For nausea and vomiting, antiemetic medications can be prescribed and the patient may be referred to a dietician for nutritional advice. For hair loss, patients might wear a wig, hat or head scarf, cut their hair short before it falls out, use a brush with soft bristles, use gentle shampoos and conditioners, and avoid using things like hair clips, pins, bobbles, hair dryers, and hair straighteners or curlers. For mouth sores, it can be helpful for patients to eat soft foods, avoid hot, spicy or acidic foods, avoid alcohol and tobacco, and drink plenty of fluids.

Some head and neck cancer websites also recommend complementary and alternative medicine (CAM) treatments such as acupuncture, chiropractic care, naturopathy, and reiki. There is no evidence to support CAM efficacy in curing cancer, however some claim that CAM can ease symptoms and side-effects.

2.4 Patient-reported outcomes following head and neck cancer

Patients can experience a number of issues ranging from the physical, emotional, and social, all of which can impact their quality of life. Some of these needs and concerns which head and neck cancer patients experience include disfigurement, trismus (difficulty opening the jaw), xerostomia (dry mouth), feeding, fear of recurrence and speech; both as a result of the cancer and as a result of treatment (S. N. Rogers, 2010). Some of these needs may be addressed if the patient informs a

healthcare professional, who can either try to address the problem themselves or refer the patient to someone who may be able to help.

A previous study has found that early stage oral cancer patients report significantly fewer concerns than late stage oropharyngeal and laryngeal (Kanatas et al., 2013). This suggests that patients with more advanced cancer experience more issues related to their quality of life.

Fear of recurrence is a very common concern experienced by patients following completion of treatment. A study conducted with 123 patients from one consultant's head and neck review clinic used the Patient Concerns Inventory (PCI), University of Washington Quality of Life questionnaire, and a fear of recurrence questionnaire to examine the prevalence of fear of recurrence concerns in patients who were at least 6 weeks post-treatment. It found that fear of recurrence was the most commonly reported concern on the PCI, with 42% of patients highlighting that concern (S. N. Rogers et al., 2010). This suggests that the most common concern for patients following treatment is fear of recurrence, however the sample was only obtained from one consultant's head and neck review clinic which limits the generalisability of the results.

A qualitative study conducted in the head and neck review clinic of one consultant interviewed 11 patients over the phone who had completed their treatment. This was after recording a recent consultation with that consultant. An interesting theme which was uncovered in the phone interviews was a reluctance to express fear of recurrence to the consultant. Participants stated that they were worried about appearing ungrateful if they were to express this (G. Ozakinci, Swash, Humphris, Rogers, & Hulbert-Williams). Therefore patients may not always feel comfortable expressing

certain concerns to their consultant. However this study was conducted using a very small sample size and did not collect data on patient socioeconomic status.

Another study conducted in the head and neck review clinic of one consultant examined the prevalence of appearance-related concerns in 204 patients attending 454 clinic appointments. All participants were disease-free and at least 6 weeks post-treatment. The sample completed the Patient Concerns Inventory (PCI) and the University of Washington Quality of Life (UW-QoL) questionnaire while waiting for their appointment. These measures allowed participants to select any concerns (including any about appearance) to discuss in their consultation, and to provide information about whether and to what extent a range of issues impacted on their quality of life. The results indicated that appearance was selected for discussion on the PCI at only 9% of appointments, and was a serious problem on the UW-QoL at only 10% of appointments. However the patients who did report problems with appearance on the UW-QoL tended to be younger than 65 years of age, female, have been diagnosed with oropharyngeal cancer, and whose cancer was at a more advanced stage (Flexen et al., 2012). This suggests that appearance-related concerns are an issue for a small percentage of patients following treatment, however because patients seem to have completed this measure more than once it is possible that these concerns are expressed multiple times by an even smaller number of patients. This would make the issue even less prevalent in this sample than it appears.

A different journal article seemingly using data from the same study, looked at the prevalence of swallowing and speech problems in the same head and neck review clinic. The authors found that 21% of patients reported swallowing problems on the UW-QoL and 17% on the PCI, whereas 7% reported issues with speech on the UW-QoL and 13% on the PCI. Patients who reported serious problems with swallowing

or speech on the UW-QoL tended to have had more advanced stage cancer, have received radiotherapy, and had undergone free-flap surgery. There were no significant associations with gender or age (Ghazali et al., 2012). This suggests that swallowing and speech concerns are slightly more prevalent than appearance-related concerns in the previous article, however it is still a fairly small percentage of patients who express these concerns. But there is the limitation that this study is conducted in the clinic of only one consultant, limiting the generalisation of such results by not only location but also consultant-related variables such as style of communication and relationship with patients. Certain styles of communication with patients may inhibit their comfort with expressing concerns, even by questionnaire.

However a longitudinal study conducted in a different part of the UK found slightly different results. Newly diagnosed head and neck cancer patients were asked to complete the UW-QoL and the M.D. Anderson Dysphagia Inventory before receiving intensity-modulated radiotherapy, and 3, 6 and 12 months after treatment had ended. This was in order to measure quality of life with regards to swallowing problems, and 61 patients initially agreed to participate. It was found that radiotherapy significantly impacted swallowing function, however this improved after 12 months although it did not return to baseline levels. Following treatment 44% of patients highlighted swallowing as an important concern on the UW-QoL (Roe, Drinnan, Carding, Harrington, & Nutting, 2014). This suggests that swallowing is an important concern for patients following radiotherapy. The percentage of patients concerned about swallowing was slightly higher in this sample than the previous study by Ghazali et al. (2012), however this is perhaps because all of the patients in this study had undergone radiotherapy. This study has the

advantage of tracking longitudinal trends in swallowing problems, however it has a smaller sample size.

These studies suggest that head and neck cancer patients report a range of issues following treatment, with fear of recurrence being the most common. However, do patients differ in terms of their experience of head and neck cancer based on their socioeconomic status?

Chapter 3: Socioeconomic status

3.1 Definition

Socioeconomic status (SES) is defined overall as both an individual's access to resources as well as their position in society compared to others (Krieger, Williams, & Moss, 1997). This is usually measured by a range of social and economic variables such as education, income and occupation, which cover the different reasons why poorer people are disadvantaged.

There are two main reasons why SES differences give rise to health inequalities. Firstly people who have fewer material resources are disadvantaged, and secondly they may also have a weaker position in society, with less prestige, fewer social connections, and fewer opportunities. Material deprivation can be defined as a lack of access to important services and resources within society, whereas social deprivation involves lack of participation in various roles, relationships, and rights within a society (Townsend, Phillimore, & Beattie, 1988). For people from low SES backgrounds, usually both material and social deprivation are important.

Social differences are relevant at the individual level but also at the community level as well. Social capital is a concept which is defined as the networks, norms and trust which facilitate the cohesion of social groups (McKenzie, Whitley, & Weich, 2002). Social groups can be neighbourhood communities, workplaces, and such, and each group is likely to have their own different norms and behaviours necessary for membership (Villalonga-Olives & Kawachi, 2017). While social capital can be beneficial to those who conform to the necessary norms, it can have a negative impact on those who do not conform (Villalonga-Olives & Kawachi, 2017). Furthermore, health behaviours can spread throughout a social group. Some of these can be positive health behaviours, however some can be damaging, for example

smoking, heavy alcohol consumption, or drug use (Villalonga-Olives & Kawachi, 2017). Some social groups, such as deprived neighbourhoods, are lacking in the resources and trust necessary to support one another that individuals find it difficult to engage in healthy behaviours and cope using unhealthy behaviours (Cattell, 2001).

The relative impact of material and social deprivation is seen in studies comparing absolute and relative poverty. Absolute poverty is where a fixed cut-off, for example monthly household income, is set and applied across different time points and different countries (Foster, 1998). So any household earning less than the cut-off is considered to be in poverty. Whereas relative poverty sets a cut-off point based on the current standard of living in a particular country or time period, therefore this cut-off point is likely to differ depending on time and place (Foster, 1998).

In other words, absolute poverty reflects lower material standards such as poor housing conditions, whereas relative poverty reflects an individual's social position in relation to others which can have a number of psychosocial outcomes (Wilkinson, 1997). Literature shows that relative poverty is a particularly important differential between people's health status indicating that differences in social position, for example as indicated by education or occupational level, are as important a consideration as income differences may be (Wilkinson, 1997).

3.2 Measures

SES can be measured in a number of ways, as described below, depending on which of these aspects of SES researchers wish to capture. These measures are sometimes employed in studies, however they are often only used to describe the study sample as opposed to being a variable included in analysis. Some studies cite participant ethnicity, age, or single-parenthood as a measure of SES, however these are

variables which can be associated with SES as opposed to being measures of it (Townsend et al., 1988). For example, while a large number of people belonging to minority ethnic groups might be at the lower end of the socioeconomic gradient, that does not mean that all ethnic minorities are low SES or that all people with low SES belong to ethnic minority groups. While inequalities stemming from SES, ethnicity, gender, and so on are related, they are distinct concepts. To treat them as though they represent the same thing hinders understanding of the key issues central to each concept. Therefore these variables will not be included in the following section.

For the next section I will focus on two main types of SES measures: area-level and individual-level.

3.2.1 Area-level measures

Area-level deprivation is sometimes used as a measure of SES. This is based on where a person lives, and how that reflects their access to material and other resources. There are several different area-level measures which have been used in research.

Indices of Multiple Deprivation (IMD) is one such measure of area-level deprivation for England. Government and census data for each postcode (which corresponds to a Lower-layer Super Output Area) across 7 domains are combined to form a score which is then used to rank each postcode area within England from most deprived to least deprived. These scores are condensed into deciles with 1 being the most deprived and 10 being the least deprived areas, although in some studies quintiles are used instead. The 7 domains used to calculate these scores are income, employment, education, health, crime, access to housing and services, and living environment (*The English Indices of Deprivation 2015*, 2015). IMD scores are publicly available

on the Department for Communities and Local Government website using a postcode-lookup tool. There is also a version of IMD for Scotland called the Scottish Indices of Multiple Deprivation (SIMD). Although the data provided is for Lower-layer Super Output Areas, which contain 1000 to 1500 residents, there is also guidance available for converting this data into electoral wards.

There are a number of advantages and disadvantages associated with using IMD as a measure of SES. IMD scores are easily accessible using postcodes and provide an overview of the deprivation present in a small area. However this does not account for individual differences present in an area, for example someone with a high level of education or income may be living in an area with a low IMD score. Therefore although their individual SES might be high, IMD would class them as living in a very deprived area. Although inequalities in health may be produced as a complex interplay between the individual and their environment, and so area-based measures can reflect this. However, research suggests that living in an urban environment can have a negative impact on an individual's mental health and wellbeing even when IMD is controlled for (Corcoran et al., 2017). Area-based measures can capture environmental influences on health inequalities such as community cohesion, lower sense of control due to the prevalence of crime, and the existence of food deserts which are related to poorer diets (Walker, Keane, & Burke, 2010).

Furthermore, some of the data used to calculate IMD scores is taken from a 10 yearly national census. Although the data used is taken from the most recent time point available, much of the data for the most recent IMD (2015) was taken from the 2012/13 tax year (*The English Indices of Deprivation 2015*, 2015). The profile of an area may have changed during this time, therefore IMD scores may not always be accurate representations of the deprivation levels in an area.

The Townsend deprivation index is also an area-level measure of deprivation, which utilises census data (Townsend et al., 1988). This measure only uses four variables: unemployment, proportion of households without a car, proportion of houses not owner occupied, and proportion of households with overcrowding (Galobardes, Shaw, Lawlor, Lynch, & Smith, 2006b; Townsend et al., 1988). When this index was devised it was based on census data from 1981 which did not utilise postcodes, therefore the authors used local authority (LA) wards as their areas of interest (Townsend et al., 1988). Compared to this measure, the IMD is a more precise area-based measure of SES because LA wards are larger areas than those which are covered by a single postcode. Furthermore LA ward boundaries are more likely to change over time, hindering analysis and comparison. The IMD is also superior in that it uses seven domains which encapsulate both material and social deprivation, in comparison to the four variables used by the Townsend deprivation index.

The Carstairs index (Carstairs & Morris, 1989) is a similar measure of area-level deprivation, which also uses census data for each postcode. However the census variables it uses are levels of male unemployment, whether households possessed a car, whether the household was overcrowded, and social class. These variables were chosen in order to reflect material deprivation (Carstairs & Morris, 1989).

In contrast, the "Broken Windows" index measures area-level deprivation using variables representative of the physical environment in a neighbourhood. This uses the variables of visible damage to properties, presence of graffiti, abandoned cars, litter, etc, and physical problems of public high school buildings as obtained from building inspection reports (D. Cohen et al., 2000). This has been used in the USA and is based on the Broken Windows theory which links neighbourhood disorder with antisocial and criminal behaviour (Gau & Pratt, 2010). While there are some

issues with this theory, such as doubts regarding whether the link between disorder and crime is causal or whether the two are even distinct concepts (Gau & Pratt, 2010), the "Broken Windows" index may be a good way of capturing elements of the physical environment related to access to resources and government funding. For example, the state of public buildings such as schools and other properties may reflect a lack of funding from the government or lower income earned by residents. This index may reflect both material and social deprivation to a degree, with disrepair resulting from inability to afford proper maintenance on local properties, as well as less trust and support afforded by the social capital of that community.

The Breadline Britain index is a consensual measure of poverty, that is, it surveys a population in order to determine what they perceive to constitute necessities. Then these results can be used to find out where individuals sit on the socioeconomic scale, based on which necessities they lack (Galobardes et al., 2006b). Such necessities can include ownership of a TV, a home without damp, and a warm waterproof coat (Pantazis & GORDON, 1997). This measures relative poverty as opposed to absolute poverty, unlike some of the previous indices mentioned, which seems to more accurately predict health outcomes (Wilkinson, 1997).

In summary, there are a number of area-level measures which can be utilised in the study of SES, each with their own advantages and disadvantages. But area-level measures may not adequately capture all aspects of SES related to an individual's socio-psychological context. What about individual measures?

3.2.2 Individual-level measures

In contrast to area-level measures, individual measures focus on various factors unique to an individual as opposed to the environment which they live in. These are

socio-political class, education level, income, employment status, occupation, and the characteristics of their housing.

3.2.2.1 Socio-political class

One measure of SES used in a number of studies is social class. An individual's social class is which hierarchical social and economic group they fit into in their society in relation to others; usually this is either lower, middle or upper class. A key component of social class is the deprivation of lower classes at the benefit of higher classes, therefore asymmetry is integral to this concept (Krieger et al., 1997). Some studies measure this using participant's perceived social class, which is a relative measure of social deprivation and takes account of more psychosocial factors and relationships than material deprivation measures. However social class is a somewhat outdated measure now; given that most individuals work in some capacity even if they are extremely wealthy, 'working class' is no longer a useful grouping.

Karl Marx's work has been very influential in the use of SES in research (Krieger et al., 1997; Muntaner, Borrell, Benach, Pasarin, & Fernandez, 2003; Muntaner, Ng, Chung, & Prins, 2015; Prins, Bates, Keyes, & Muntaner, 2015; Wright, 1993). His conception of social class shares a number of similarities with other researchers' definitions of the concept (Krieger et al., 1997; Muntaner et al., 2015; Wright, 1993). Marx stated that social class was defined by an individual's relation to the means of production (e.g. factories and land), and those who controlled the means of production were exploiting capitalists or bourgeoisie, whereas those who did not were exploited workers or proletariat (Krieger et al., 1997; Wright, 1993). There is conflict between the opposing groups (i.e. the bourgeoisie and the proletariat) (Galobardes, Shaw, Lawlor, Lynch, & Smith, 2006a; Galobardes et al., 2006b).

There are two measures of social class directly based on Marx's work: Wright's social class classification and Lombardi et al's social class classification.

Wright's social class classification looks at the degree to which an individual possesses three types of assets: capital, organisational, and credential (skills). This is then translated into 12 groups: capitalist, small employer, petty bourgeoisie, expert manager, skilled manager, non-skilled manager, expert supervisor, skilled supervisor, non-skilled supervisor, experts, skilled workers, and non-skilled workers (Galobardes et al., 2006b; Krieger et al., 1997). This measure has been used in several different countries (Krieger et al., 1997; Muntaner et al., 2003), and reflects both material and social deprivation with relationships between other individuals in an organisation, as well as the possession of skills.

Lombardi et al's social class classification was developed in Brazil. It is similar to Wright's classification, however it has only 6 groups: underproletariat, typical proletariat, atypical proletariat, traditional small bourgeoisie, new small bourgeoisie, and bourgeoisie (Galobardes et al., 2006b; Lombardi et al., 1988).

3.2.2.2 Education

Education is an individual measure of SES, since access to education is an important social and economic resource which can influence an individual's future job prospects and financial position, as well as the confidence in which they behave in different environments. Education may be necessary in order to access the social capital of certain groups, and enable an individual to build rapport with others of a similar SES level. Education level can be measured using the age at which an individual leaves formal education or the highest qualification which someone holds (Liberatos, Link, & Kelsey, 1988).

Education level can be a relatively easy form of data to collect as it is easy for participants to understand (and not misinterpret), as well as being less uncomfortable for participants to answer than measures such as income. However individuals born in earlier decades tend to have lower levels of education despite being classed by other measures, such as occupation, as possessing a higher level of SES, therefore this makes comparison with individuals belonging to later cohorts difficult (Galobardes et al., 2006a; Hadden, 1996). Furthermore educational opportunities for disadvantaged groups such as women and ethnic minorities have changed significantly over several decades, therefore influencing education data in earlier birth cohorts (Galobardes et al., 2006a; Hadden, 1996; Liberatos et al., 1988).

3.2.2.3 Income

Income is another often used individual measure of SES. Generally it is measured by asking participants to provide details of their absolute income, their income relative to the current level of poverty, or to choose from a set of pre-defined categories. This can be in terms of individual income or household income. Income can impact an individual's access to material resources, as well as being linked with other SES variables such as education and occupation. Income can be difficult to collect data on as it can be a sensitive subject for some participants (Galobardes et al., 2006a; Liberatos et al., 1988).

3.2.2.4 Employment

Employment status has been used by some studies as a measure of SES. Typically it will be measured as either 'employed' or 'unemployed' at least, but sometimes other categories such as 'retired', 'off sick', 'volunteer', or 'student' may also be recorded. Some studies also distinguish between full-time and part-time employment, although

employment status is not often used as an SES measure (KLEIN-HESSELINK & SPRUIT, 1992).

Employment as a measure of SES can reflect access to earned income and any material benefits which may be associated with a particular job, and thus influence access to material resources and financial security (Townsend et al., 1988). However it is also reflective of social capital, since people who are without employment may be excluded from accessing certain forms of social capital.

3.2.2.5 Occupation

Another individual measure of SES is occupation. This can be either an individual's current or longest held occupation, or in some cases parental occupation or the occupation of the 'head of the household' might be used (Galobardes et al., 2006a). The Office for National Statistics (ONS) is a British government agency which has come up with the standard occupational classification (SOC). This classifies occupations within the UK into nine ranked groups according to the work involved and the skills required. The nine groups (from highest to lowest ranked) are: Managers, directors and senior officials, Professional occupations, Associate professional and technical occupations, Administrative and secretarial occupations, Skilled trades occupations, Caring, leisure, and other service occupations, Sales and customer service occupations, Process, plant, and machine operatives, and Elementary occupations.

The ONS SOC lists each group along with examples of occupations which fall into each category, to help individuals and researchers choose the appropriate category which applies to them. However in collecting data on this, participants can find it confusing when asked to allocate themselves to a particular group. Or if the

researcher simply asks for their occupation in order to allocate the participant themselves, some participants may give confusing or less detailed answers which make accurate allocation to groups difficult. Furthermore, the nature of certain occupations changes over time requiring the measure to be updated every few years or so (Galobardes et al., 2006b).

3.2.2.6 Housing characteristics

Collecting data on various housing characteristics can be another measure of SES specific to an individual or family. These typically capture the living circumstances of an individual, which can be influenced by other SES indicators such as income. This differs from area-level measures because housing characteristics measures look at an individual's specific living conditions, as opposed to the neighbourhood or wider area as a whole.

One characteristic is housing tenure which measures whether an individual owns their home or rents from a landlord. Another characteristic is housing amenities which measures things like access to running water in the house, central heating, indoor toilets, fridge, washing machine, or phone (Galobardes et al., 2006a; Howden-Chapman, 2004).

An issue with these measures is that their usefulness depends on the population studied. For example, many people in developed countries such as the UK now have indoor toilets, therefore that measure would not be a useful comparison in such populations. However that measure may be useful for examining childhood SES in older cohorts of developed countries. Another measure used is car ownership, although this also suffers from the same geographical and cohort issues (Abramson, Gofin, Habib, Pridan, & Gofin, 1982; Galobardes et al., 2006a).

Sometimes housing conditions are measured with regards to things like the presence of damp, overcrowding, or the number of rooms (Galobardes et al., 2006a; Howden-Chapman, 2004).

In summary, there are a range of both individual and area-level measures of SES which capture different aspects of SES. But how do these aspects of SES relate to the health inequalities experienced by individuals at the lower end of the socioeconomic gradient?

3.3 Health inequalities related to SES

It is obvious that the causes of inequalities in health is due to differences in an individual person's lifestyle choices such as poor diet, which might be restricted by a limited income, however there is an expansive literature showing that the environment which people live in also has a significant effect. For example if they live in a poor neighbourhood there are often fewer shops which sell healthy food, which creates food deserts, making healthy choices harder (Walker et al., 2010). So measures of the area a person lives in may reflect these wider factors. People's behaviour may also be impacted by socio-psychological factors which means that income related factors are only in part a cause of health inequalities.

Research suggests that health varies across the socioeconomic gradient, with morbidity and mortality rates for both adults and children increasing as you descend further down the socioeconomic scale (Marmot, 2005). This has been found to affect a vast range of conditions including mental health issues (Fryers, Melzer, & Jenkins, 2003), obesity and diabetes (Everson, Maty, Lynch, & Kaplan, 2002), and lung, breast, and prostate cancers (Clegg et al., 2009). Based on the health inequalities literature a number of researchers, including Michael Marmot, have recommended

proportionate universalism as a means to address such inequalities. While they seem to disagree on the specific details of such a policy, a common theme seems to be the equitable distribution of resources (Carey, Crammond, & De Leeuw, 2015; Marmot et al., 2008).

As described in Chapter 2, head and neck cancer is a chronic condition with a variety of outcomes which can severely impact an individual's quality of life. But are there socioeconomic inequalities in head and neck cancer as well?

3.3.1 Socioeconomic differences in incidence and outcomes of head and neck cancer

Research suggests that individuals of low socioeconomic status (SES) are more likely to develop head and neck cancer than high SES individuals (Auluck et al., 2014; Colevas, 2014; Conway et al., 2010; Hwang, Johnson-Obaseki, McDonald, Connell, & Corsten, 2013; Thorne, Etherington, & Birchall, 1997). This seems to be mainly mediated by alcohol consumption and smoking rates (Conway et al., 2010). A case-control study conducted in France found a significantly higher risk of developing head and neck cancer for individuals with lower education levels, manual occupations, or living in deprived areas as measured by the European Deprivation Index (Bryere et al., 2017).

Recent studies found that low SES head and neck cancer patients experience poorer quality of life as measured by the UW-QoL, particularly in the socio-emotional subscale, and worse survival rates as measured by the Office of National Statistics and tracked between 2008 and 2014 following treatment for oral cancer (Ghazali et al., 2013; Rylands et al., 2016a, 2016b; Woolley et al., 2006).

There is some evidence to suggest that patients from the most deprived areas are not referred for cancer treatment as quickly as patients from less deprived areas (Brocklehurst, Rafiq, Lowe, & Rogers, 2012), however another study found the opposite effect in which patients from more deprived areas were referred more quickly (S. N. Rogers et al., 2007). Some studies have also found an association between education, occupation, or deprivation and patient delay in presenting head and neck cancer symptoms (Noonan, 2014), however others have found no such association between delay and patient SES. For example, Adrien et al., (2014) found no significant differences between early stage and late stage diagnosed patients in terms of deprivation, education, occupation, or income (Adrien, Bertolus, Gambotti, Mallet, & Baujat, 2014). Rogers et al., (2007) also found no significant association between patient delay and Indices of Multiple Deprivation score from a sample of 559 patients who underwent surgery for oral and oropharyngeal squamous cell carcinoma (S. N. Rogers et al., 2007). This suggests that the link between lower SES, lower survival rates, and poorer quality of life may be more complex than originally thought.

These studies suggest that individuals from a lower socioeconomic background are more likely to develop head and neck cancer, and tend to suffer worse quality of life and lower survival rates following treatment in comparison to their higher SES counterparts. However this effect may not simply be due to differences in presentation delay, and there may be other factors at play.

So SES can impact an individual's health in a variety of ways, based on both their environment and the socio-psychological context in which they live. However, when an individual is in the care of the healthcare system, does the content and quality of their interactions with healthcare professionals also impact their health?

Chapter 4: Doctor-patient communication

4.1 What is communication?

A broad definition of communication is an organism's discriminatory response to a stimulus, so if an organism does not respond to a stimulus then no communication has taken place (Stevens, 1950). This encompasses not only interactions between humans (for example, an individual's response to a question posed by another person), but also interactions between animals and other organisms (for example, a cat hissing at another cat impinging on its territory). However, for the purpose of this PhD we are only interested in interactions between humans. This can be through spoken language, writing, and nonverbal behaviours such as body language, and can take place in a variety of contexts. The context of interest here, is healthcare settings. Specifically, appointments.

An appointment between a healthcare professional and a patient typically consists of four stages: an opening (during which a problem may be presented by the patient), gathering medical history (in which the healthcare professional will ask questions to gain more information about the problem), a physical examination of the patient, and finally a closing stage during which the healthcare professional will give a summary of what they have deduced thus far, and any next steps to take (for example, treatment, further testing, or referral to a specialist) (Fisher, 1984). Although this structure is likely to differ for certain types of appointments, such as screening.

This process can vary depending on the setting and the patient, and might be handled differently depending on the provider's communicative style. Both the patient and the provider are involved in this interaction, however the degree to which both parties are involved can vary. There are some theories as to what the ideal style of communication should be in such interactions.

4.2 The medical interaction

A medical appointment is an interaction between at least two parties, the healthcare professional and the patient. However sometimes a third party might come into play: the patient's relative or close friend. Some patients prefer to bring a friend or relative with them to sit in on their appointments and provide support. Sometimes these individuals might also ask the healthcare professional questions themselves, provide information about the patient, or even prompt the patient to ask questions. However, because our focus is on the interaction between the patient and healthcare provider, this aspect of the interaction is outside of the remit of this PhD.

4.3 Healthcare professional communication behaviours

According to Suzanne Kurtz, healthcare provider communication skills are comprised of three elements: content, process, and perception (Kurtz, 2014). Content is what the provider actually says, whereas process is how the provider says it. In contrast, perception is the awareness of the provider's own thought processes and biases. While this final element is quite different from the other two, all three are linked (Kurtz, 2014).

There are various communication behaviours which can be displayed by healthcare professionals during consultations. These include providing information to the patient, asking questions, building rapport, encouraging the patient to ask questions or express their opinions, and checking that the patient understands what has been said (Ronald M Epstein & Street JR, 2007). These are typically patient-centred behaviours which can provide space for the patient to speak more, however there are some behaviours which are utilised by healthcare professionals which can be more paternalistic.

Such behaviours include ignoring patients' questions, lack of engagement in rapport-building, and dismissing or shutting down concerns which a patient might raise. These behaviours tend to reduce space within the consultation for the patient to talk, discouraging further input from them.

Even nonverbal behaviours such as eye contact and body language can encourage or discourage further input from a patient. If a healthcare professional is staring at their computer, writing notes, or fidgeting while a patient is talking, this may be less encouraging than someone who is making eye contact, facing the patient, and demonstrating that they are listening fully to what they are saying.

Each healthcare professional has their own communication style which will be comprised of a mixture of these behaviours. Even if a healthcare professional has a very patient-centred style of communication, they may still occasionally use behaviours which reduce space. Communication style may vary depending on a number of factors.

4.3.1 Type of healthcare provider

One such factor which influences communication style may be the type of healthcare provider. Previous research has found that there are differences between doctors and nurses in terms of their communication with patients. Sandhu et al., (2009) compared the communication styles of Emergency Nurse Practitioners (ENPs), Senior House Officers (SHOs), specialist registrars, and general practitioners in a British emergency department using the Roter Interaction Analysis System (RIAS) (H Sandhu, Dale, Stallard, Crouch, & Glucksman, 2009). They analysed 296 videotaped consultations and found some significant differences between the nurses and physicians. SHOs asked significantly more questions about the patient's presenting

medical condition, whereas ENPs asked patients more questions about their current medical care. SHOs were more likely to demonstrate understanding towards patients than ENPs, however registrars were more likely to criticise or disagree with patients than ENPs. SHOs and registrars were more likely to check the patient's understanding and ask for their opinion than ENPs. ENPs and general practitioners were significantly more likely to provide education and counselling to patients, with ENPs providing more information to patients about their current medical care than SHOs. There was no significant difference in the length of consultations between providers (H Sandhu et al., 2009).

This study suggests that while SHOs were more likely to engage patients by checking their understanding and asking their opinions, ENPs were more likely to encourage participation through provision of information and education regarding their wider medical care (H Sandhu et al., 2009). However the majority of physicians participating in this study were male, in comparison with only two of the six ENPs being male. Given that provider gender can influence communication style (as will be covered in section 4.3.5.1), this may have affected the results of the study.

A study conducted by Byrne et al., (2000) compared patient satisfaction, communication, and wait times in an emergency department for patients seen by either ENPs in a Minor Accident Treatment Service or a Minor Injuries Unit, or SHOs as part of a traditional emergency department (Byrne, Richardson, Brunsdon, & Patel, 2000). They found that patients who had been seen by an ENP were significantly less worried about their health after the consultation, than those seen by an SHO. Furthermore, all patients seen by ENPs felt that they had sufficient time to discuss everything, compared to 11.9% of patients seen by SHOs. Patients seen by ENPs received significantly more information and advice regarding their health, than

those who were seen by SHOs. Patients who were seen by ENPs were also significantly more likely to receive written instructions or advice on who to contact if further help is needed, than those seen by SHOs. Waiting times were significantly longer for patients seeing SHOs, than those seeing ENPs, however consultations with ENPs were significantly longer than those with SHOs (Byrne et al., 2000).

This study suggests that ENPs spent more time with patients, providing them with more information and advice, and resulting in higher patient satisfaction.

The previous two studies compared nurse and doctor communication styles within emergency departments, however Vinall-Collier et al., (2016) conducted their study within rheumatology outpatient clinics. They analysed 44 nurse specialist consultations and 63 consultations with physicians across nine different rheumatology clinics, using RIAS. They found that the nurse specialist consultations were significantly longer than the doctor consultations, with nurse specialists asking more questions and spending more time building rapport with patients. Furthermore, patients engaged significantly more in building rapport with nurse specialists than with doctors (Vinall-Collier, Madill, & Firth, 2016). This suggests that nurse specialists spent more time with patients, and built more rapport with them, however unlike the Sandhu et al., (2009) study there was no significant difference in terms of provision of education and counselling to patients. One reason for this could be due to differences between the emergency department and outpatient clinics, although this study also suffered the same limitation of recruited nurses being mostly female while most recruited doctors were male.

Given the differences in communication style between nurses and doctors, for the purpose of this PhD we have chosen to focus on doctors due to their role in head and

neck cancer consultations. However this brings us to an important point: how does healthcare setting influence doctor-patient communication?

4.3.2 Healthcare setting

Studies in the field of doctor-patient communication have been conducted in a variety of settings, for example General Practice (Little et al., 2001; Nicola Mead, Bower, & Hann, 2002; Scott, Shiell, & King, 1996; Seale, Anderson, & Kinnersley, 2006), cancer outpatient clinics (G. Ozakinci et al.; Velikova, Brown, Smith, & Selby, 2002; Zhou, Humphris, et al., 2015; Zucca, Sanson-Fisher, Waller, Carey, & Boadle, 2017), inpatient hospital care (Clever, Jin, Levinson, & Meltzer, 2008), and palliative care (Detmar, Muller, Wever, Schornagel, & Aaronson, 2001; Friedrichsen, Strang, & Carlsson, 2000; L A Siminoff, Fetting, & Abeloff, 1989).

However there do not appear to be any studies which explore whether doctor-patient communication differs between different healthcare settings. Based on this, we decided not to limit our systematic mapping review inclusion criteria by study setting. However the studies outlined in chapters 8 and 9 focused specifically on head and neck oncology follow-up consultations.

This again leads us to another point, though: does the patient's condition influence doctor-patient communication?

4.3.3 Type of condition

As with healthcare setting, there are a variety of patient conditions which are represented in the doctor-patient communication literature. For example, breast cancer (L A Siminoff et al., 1989; Laura A Siminoff, Graham, & Gordon, 2006), arthritis (Donovan & Blake, 2000), HIV (Schneider, Kaplan, Greenfield, Li, & Wilson, 2004; Sullivan, Stein, Savetsky, & Samet, 2000), advanced AIDS (Curtisa,

Patrick, Caldwell, Greenlee, & Collier, 1999), and head and neck cancer (Zhou, Humphris, et al., 2015).

Dowsett et al., (2000) did not compare different patient conditions, however they did examine how preference for doctor communication style varied depending on whether the participant watched a video of a consultation with a poor prognosis or a good prognosis. The participants were breast cancer patients and their friends and relatives. They were more likely to express greater satisfaction with a patient-centred communication style for diagnosis if they had watched a poor prognosis video, whereas they were more satisfied with a doctor-centred communication style for treatment during the good prognosis video (Dowsett et al., 2000).

This study suggests that patient prognosis may influence doctor-patient communication, however again there do not appear to be any studies which explore whether doctor-patient communication differs by patient condition. So does the type of consultation affect doctor-patient communication then?

4.3.4 Type of consultation

Various different consultation types are represented in the doctor-patient communication literature. For example, follow-up consultations (Franco et al., 2017; Lelorain et al., 2018; Mellblom et al., 2014; Mellblom et al., 2016; Thomsen, Soelver, & Holge-Hazelton, 2017; Zhou, Humphris, et al., 2015), screening discussions (Bao, Fox, & Escarce, 2007; Chalian, Khoshpouri, & Assari, 2019; Fox et al., 2009; Gao, Burke, Somkin, & Pasick, 2009; Ling, Klein, & Dang, 2006; Underhill & Kiviniemi, 2012), and emergency department attendances (Crane, 1997; Rhodes et al., 2004; Wissow et al., 1998).

But there doesn't seem to be any studies which explore whether doctor-patient communication differs by type of consultation. What about the personal characteristics of the doctor? Do those influence the doctor's communication style?

4.3.5 Doctor characteristics

Unlike the previous sections, numerous studies have explored how doctor communication behaviours differ according to the sociodemographic characteristics of doctors. Doctor communication styles have been shown to vary based on two of these factors: gender and ethnicity (Cooper-Patrick et al., 1999; Debra L. Roter, Hall, & Aoki, 2002; Richard L. Street, 2002).

4.3.5.1 Doctor gender

Roter et al., (2002) conducted a meta-analysis of 26 studies reported in 29 articles in order to examine the effect of doctor's gender of their communication behaviours. They found that consultations with female doctors were 2 minutes longer than those with male doctors, and during these consultations female doctors engaged in more partnership building and socioemotional talk, as well as asking more questions about psychosocial information. Slightly different results were found for the 2 studies conducted in obstetric and gynaecology settings, where socioemotional talk was practiced by more male doctors than females. However, there were no significant differences between genders in terms of biomedical information provision or social talk (Debra L. Roter et al., 2002). This suggests that female doctors have a more socioemotional style of communication, although this may differ slightly between specialties.

Roter et al., (2004) found similar results when they later conducted another meta-analysis on the same topic, also finding that patients who saw female doctors spoke

more and provided more information to the doctor than those seeing male doctors (Debra L. Roter & Hall, 2004). These results were also found in an earlier study by the same authors, who analysed gender differences in doctor and patient communication behaviours in 100 appointments with internists (Hall, Irish, Roter, Ehrlich, & Miller, 1994). The results were also replicated in a study across both Canada and the USA in outpatient clinics of academic, community Veteran's Affairs, and private hospitals (D. Roter, Lipkin, & Korsgaard, 1991).

Janssen et al., (2012) conducted a systematic review of studies examining doctor-patient communication in gynaecological and obstetric settings, in order to look at the influence of doctor gender. Their review included 9 studies, and they found that female doctors were more likely to encourage shared decision-making, made more eye contact, provided more information, acknowledgments and support, used more affective statements, and overall engaged in a more patient-centred style of communication than male doctors. Significantly more patients preferred to see a female doctor, which may be partly explained by the gender differences in doctor communication style (Janssen & Lagro-Janssen, 2012).

Sandhu et al., (2009) conducted a systematic review of studies examining how gender concordance influences doctor-patient communication. Ten studies were included in the review, and they found that consultations between male doctors and female patients were the least patient-centred with doctors spending more time conducting physical exams and discussing screening than exploring options for self-management. On the other hand male doctors spent more time discussing self-management with their male patients. Appointments between female doctors and female patients were the most patient-centred, containing more talk overall as well as specifically psychosocial and biomedical talk. There is a lot of tension during

consultations between female doctors and male patients, however doctors smiled more and used less technical language during these appointments in an attempt to engage the patient. There were conflicting findings regarding gender concordance and consultation length (Harbinder Sandhu, Adams, Singleton, Clark-Carter, & Kidd, 2009). This suggests that gender concordant consultations tend to result in more patient-centred behaviours from the doctor.

Cooper-Patrick et al., (1999) conducted a telephone survey of 1816 individuals who had recently attended a primary care practice, in order to examine how involved they had been in their consultation and how that related to patient and doctor gender. Patients of female doctors reported that they were significantly more involved in the consultation, than those who had seen a male doctor. However neither patient gender nor gender concordance was significantly associated with degree of involvement in consultations (Cooper-Patrick et al., 1999). This suggests that female doctors are more likely to provide room for patients to become more involved in their healthcare, however the data for this study is exclusively patient self-report so it may not accurately reflect what happened in the consultations.

Meeuwesen et al., (1991) analysed 85 General Practitioner (GP) appointments and found that consultations with female GPs were significantly longer than consultations with male GPs. Furthermore, male GPs were significantly more directive towards their patients and provided more advice, whereas female GPs provided more acknowledgments and information, being overall less directive and more attentive towards their patients (L. Meeuwesen, Schaap, & Vanderstaak, 1991). This suggests that male GPs engage in more doctor-centred behaviours, however the male GPs were on average 9 years older than the female GPs, so this may reflect differences in what they were taught as part of their medical degree.

Franks et al., (2003) analysed the appointments of 41,292 patients with 1470 primary care doctors in the USA to examine the relationship between doctor gender and doctor communication behaviours. They found that appointments with female doctors were longer, and more likely to result in referrals or follow-up tests than those with male doctors (Franks & Bertakis, 2003).

Roter et al., (1999) analysed 87 prenatal appointments with 21 obstetricians in order to examine the influence of doctor gender on communication within the appointment. In contrast to previously mentioned studies, they found that male doctors conducted significantly longer appointments than their female colleagues. Male doctors were also more likely to check the patient's understanding and express concern than female doctors, however patients reported being significantly more satisfied with female doctor consultations than consultations with male doctors (D. L. Roter, Geller, Bernhardt, Larson, & Doksum, 1999).

These studies suggest overall that female doctors tend to employ a more patient-centred style of communication and spend more time with their patients, however a few studies have reported contradictory findings.

4.3.5.2 Doctor ethnicity

Ferguson et al., (2002) conducted a systematic review of studies examining how patient and physician ethnicity influences doctor-patient communication. They included 21 studies in their review, most of which looked at language spoken or only focused on patient ethnicity. However two studies looked at physician ethnicity, one of which found no significant difference in patient ratings of physicians based on physician ethnicity. Patients also reported more involvement in consultations which were concordant. In contrast, the other study found a small but significant difference

in ethnic minority patients rating of physicians, where minority physicians were rated less favourably than non-minority physicians (Ferguson & Candib, 2002).

Cooper-Patrick et al., (1999) in the same study described earlier also looked at how patient and doctor ethnicity influenced patient involvement in consultations. They found that patient reported involvement did not significantly differ by doctor ethnicity, however African American patients reported that they had been less involved in the consultation than their white counterparts. Furthermore, race concordance was significantly associated with greater patient involvement in consultations (Cooper-Patrick et al., 1999). However the majority of the 64 doctors in the study were white (56%) compared to only 25% of the doctors being African American, which may have skewed the results.

Street et al., (2007) audio-recorded and analysed the outpatient appointments of 207 patients with 29 doctors in order to examine the influence of physician ethnicity on doctor communication behaviours. The only significant difference found was that doctors of Asian descent showed less positive affect than their white and African American colleagues (R. L. Street, Gordon, & Haidet, 2007).

Gordon et al., (2006) audiotaped and analysed the appointments of 137 patients with 15 doctors and two physician's assistants attending thoracic surgery or oncology clinics at a Veteran's Affairs Medical Centre. Although they did not explicitly look at the influence of doctor ethnicity, they found that African American patients received less information and participated less actively in their consultations than white patients. Furthermore, patients who were the same ethnicity as their doctor received more information and more actively participated in their consultation than

patients of a different ethnicity to their doctor (Gordon, Street Jr., Sharf, & Souchek, 2006).

These studies suggest that physician ethnicity alone may have little influence on doctor communication behaviours in comparison to patient ethnicity and concordance.

4.3.6 Different patient groups

Although there will be differences between doctors in terms of the behaviours used by them, there will also be differences in terms of how each doctor responds to patients of differing backgrounds and groups. For example, previous research has found that doctors interact with patients differently depending on their SES, gender, age, and ethnicity (Cooper-Patrick et al., 1999; Richard L. Street, 2002; R. L. Street et al., 2007; Verlinde et al., 2012; Waitzkin, 1985).

4.3.6.1 Patient gender

Street et al., (2003) audiotaped and analysed consultations with 135 patients and 20 family practice and internal medicine doctors. They found that doctors were significantly more likely to encourage male patients to ask questions, express their opinions or participate in decision-making than female patients (R. L. Street, Krupat, Bell, Kravitz, & Haidet, 2003).

Tabenkin et al., (2004) recorded and analysed 3384 outpatient appointments with 138 family doctors. They found no significant difference by patient gender in terms of consultation length, however more time was spent on physical exams, screening tests, and counselling for female patients than male patients. In contrast, male patients received more discussion of self-management behaviours necessary for active involvement in their own healthcare (Tabenkin, Goodwin, Zyzanski, Stange,

& Medalie, 2004). These studies suggest that doctors are more likely to encourage men to actively participate in their care, than women.

In contrast, Waitzkin (1985) analysed 336 appointments with 314 patients and 34 doctors. They found that female patients received more information during their consultations than male patients (Waitzkin, 1985).

Buller et al., (1987) conducted a survey of 219 patients, and while they did not look at the direct influence of patient gender on doctor communication behaviours, they did examine whether this variable mediated communication style and satisfaction with care. They found that patient gender did not mediate the effect of doctor communication style on patient satisfaction (Buller & Buller, 1987). This suggests that patient gender may only have a limited influence over doctor communication behaviours, however there don't seem to be many studies which examine the effect of patient gender in comparison to those which look at physician gender.

4.3.6.2 Patient age

The study carried out by Street et al., (2003) which was outlined in the previous section, also looked at the effect of patient age on doctor communication behaviours. They found that patient age had no significant association with whether doctors encouraged patients to ask questions, express their opinions, or be involved in decision-making (R. L. Street et al., 2003).

The study by Buller et al., (1987) described earlier, also examined patient age and found that it did not mediate the effect of doctor communication style on patient satisfaction with care (Buller & Buller, 1987).

Ford et al., (1996) analysed 117 outpatient consultations with five oncologists at a Medical Oncology department in a London hospital. Their results suggest that the

oncologists provided patients in the younger age group (21-40 years) with more information and were more responsive to their emotions, than patients in the older age group (41-74 years). However due to the small sample size it was not possible for the authors to determine whether this was due to patient age, or because younger patients were more likely to have a better prognosis (Ford, Fallowfield, & Lewis, 1996).

In contrast, the study by Waitzkin (1985) outlined earlier also examined the effect of patient age on doctor communication behaviours. They found that older patients received significantly more information from doctors, however doctors spent more time giving information to middle aged patients compared to younger and older patients (Waitzkin, 1985).

Kerr et al., (2003) surveyed 990 breast cancer patients in order to examine the influence of patient age on doctor-patient communication. They found that patients under the age of 50 were more likely to report that the information they received was unclear or insufficient, compared to patients over 50 years old. However patients in the older age group (50 or older) reported that they received unclear information if they were treated at larger hospitals (Kerr, Engel, Schlesinger-Raab, Sauer, & Holzel, 2003). This suggests that younger patients receive less information compared to older patients, however this could simply be a result of hospital size since the younger patients in the sample were more likely to be treated at large hospitals.

Siminoff et al., (2006) analysed consultations between 405 newly diagnosed breast cancer patients and 58 oncologists. They found that oncologists gave significantly more information to patients who were younger than 60 years old, in comparison to patients over the age of 60 (Laura A Siminoff et al., 2006).

The findings of research studies examining the effect of patient age on doctor communication behaviours, appear to be contradictory. Some studies have found no effect of patient age, while others have found both positive and negative associations.

4.3.6.3 Patient ethnicity

Schouten et al., (2006) conducted a systematic review of studies examining the effect of culture and ethnicity on doctor-patient communication. Their review included 14 papers, and they found that in most of the studies doctors used less affective behaviours such as rapport building, social talk, and empathy with ethnic minority patients than with white patients. However some of the studies found no effect of patient ethnicity or the opposite effect. There were also conflicting findings regarding differences in consultation length (Schouten & Meeuwesen, 2006).

Meeuwesen et al., (2006) analysed consultations with 144 patients and 31 GPs in the Netherlands in order to examine whether doctor communication behaviours differed based on whether the patient was native Dutch or a non-western immigrant. Most of the immigrant patients who participated were from Turkey or Morocco. They found that consultations with Dutch patients were significantly longer than those with immigrant patients, and that GPs used more empathy and other affective behaviours with Dutch patients (Ludwien Meeuwesen, Harmsen, Bernsen, & Bruijnzeels, 2006).

Street et al., (2005) analysed 279 consultations with a sample consisting of primary care, lupus, and lung cancer patients. They found that doctors used more reassurance, encouragement, and praise with white patients than with ethnic minority patients. These behaviours were particularly lacking in consultations with African American

patients, compared to those with Hispanic, Asian-American, and "other" patients (R. L. Street, Gordon, Ward, Krupat, & Kravitz, 2005).

The study conducted by Street et al., (2007) outlined earlier, also looked at the effect of patient ethnicity on doctor communication behaviours. They found that doctors were more dominant and angry towards African American patients than white or Hispanic patients (R. L. Street et al., 2007).

The study by Siminoff et al., (2006) outlined earlier also examined the effect of patient ethnicity on doctor communication behaviours. They found that doctors provided significantly more information and engaged in more rapport building with white patients, than with patients from other ethnic backgrounds (Laura A Siminoff et al., 2006).

In contrast, the study conducted by Street et al., (2003) also looked at the effect of patient ethnicity on doctor communication behaviours. They found no significant differences with regard to whether doctors encouraged patients to ask questions, express opinions, or be involved in decision-making (R. L. Street et al., 2003).

The majority of these studies suggest that doctors engage in fewer patient-centred behaviours with ethnic minority patients than with white patients, however some studies have found no such effect.

4.3.6.4 Patient SES

Several studies have found that doctors communicate with patients differently based on patient SES. Within these studies SES has been measured using variety of different indicators.

A systematic review of quantitative studies on SES differences in doctor-patient communication reviewed 20 studies published between 1965 and 2011. It found that

there were notable SES differences in doctor-patient communication across a range of patient groups and healthcare settings. Doctor-patient communication encompassed a number of patient and provider behaviours including rapport-building, question asking, information provision, listening, and expression of opinions and emotions. It concluded that low SES patients were approached in a more directive manner by healthcare professionals than high SES patients (Verlinde et al., 2012). This was an update of a previous review conducted in 2005 (Verlinde et al., 2012; S. Willems et al., 2005). Most of the studies (12) were conducted in a primary-care setting, with the others taking place in multipurpose clinics, pediatric departments, breast cancer treatment programs, veteran's healthcare practices, oncology practices, households, and a meta-analysis of a range of settings.

Primary care physicians were less likely to have discussed screening with low income and low educated patients than high income and more educated patients (Bao et al., 2007). General Practitioners (GPs) were less likely to report listening, explaining and giving advice to low social class patients, and reported spending more time examining these patients than patients from higher social classes (Martin et al., 1991). Oncologists spent more time trying to build rapport with high income and high educated breast cancer patients than lower income and low educated patients (Laura A Siminoff et al., 2006).

A meta-analysis found that patients from low social classes received more information during medical consultations than patients from higher social classes (Hall, Roter, & Katz, 1988). A telephone survey conducted in New Jersey in the USA with 1,109 overweight or obese adults found that low income patients were less likely to report receiving advice to lose weight from a healthcare professional in the last 12 months, in comparison to patients with a higher income. This effect remained

even when health insurance status was controlled for (Lorts & Ohri-Vachaspati, 2016). However the self-report nature of this study is a weakness.

These studies suggest that doctors tend to employ fewer patient-centred behaviours with low SES patients, than those who are higher up the socioeconomic gradient.

Furthermore, a study conducted in France with 585 patients and 27 GPs found that GPs were more likely to overestimate the health of low educated patients (as measured by their highest qualification) than their higher educated counterparts, with low educated patients perceiving their health to be significantly worse than their GP perceived it (Kelly-Irving et al., 2011). This could potentially arise from poorer doctor-patient communication and have a negative impact on low educated patient's access to treatment and support.

In contrast, a study conducted in Scotland using 107 video recorded GP consultations with 8 GPs was analysed using Verona Coding Definitions of Emotional Sequences (VRCoDES), which is a method of quantifying patient expression of emotions and doctors responses. Patient SES was measured using the Scottish Indices of Multiple Deprivation (SIMD), which is a version of the English Indices of Multiple Deprivation adapted for use in Scotland. The results suggested that GPs were more likely to respond to deprived patients concerns and cues with acknowledgment, even after the presence of more than two long-term conditions was controlled for (Zhou, Lundy, Humphris, & Mercer, 2015). This suggests that although GPs may be more likely to acknowledge low SES patient's concerns, they may not necessarily be exploring these issues, which might influence access to treatment and referrals.

4.4 Patient communication behaviours

Conversely, a patient's behaviours can also impact the interaction which takes place within a consultation. Some behaviours which can be displayed by patients include asking questions, raising concerns, involvement in making decisions regarding their healthcare, expressing opinions, preferences or emotions, and building rapport. Such behaviours are necessary in order for patient-centred care to take place (Ronald M Epstein & Street JR, 2007), however not all patients engage in these behaviours. Some patients prefer a more passive approach to their consultations, allowing the doctor to take more control over the interaction. Even if a doctor provides space for a patient to speak more within a consultation, the patient may not necessarily take advantage of that opportunity.

4.4.1 Patient characteristics

The extent to which patients engage in these communication behaviours also differ depending on their gender, SES, age, and ethnicity (Degner & Sloan, 1992; Patel & Bakken, 2010; D. E. Stewart, Abbey, Shnek, Irvine, & Grace, 2004; Verlinde et al., 2012).

4.4.1.1 Patient gender

Bylund et al., (2002) analysed 100 videotaped consultations between patients and general internists to examine the influence of patient gender on patients' expression of emotion. They found that while there were no significant differences in terms of the number of emotions expressed during consultations, female patients expressed significantly more intense emotions than male patients (Bylund & Makoul, 2002).

The study by Street et al., (2005) outlined earlier also looked at patient gender. They found that female patients were more likely to express concerns and negative emotions during consultations than male patients (R. L. Street et al., 2005).

Street et al., (2003) found similar results. Female patients asked more questions, expressed more concerns, and gave more assertive responses than male patients (R. L. Street et al., 2003).

This was confirmed by Tabenkin et al., (2004) who found that female patients raised more emotional issues during consultations than male patients (Tabenkin et al., 2004).

Krupat et al., (2000) conducted a survey of 400 primary care physicians and 1020 patients. They found that female patients preferred to be more involved in decision-making and to have a more equal relationship with their doctor than male patients (Krupat et al., 2000).

These studies suggest that female patients express more intense emotions during consultations, engage in more patient-centred behaviours, and have a greater preference for involvement in decision-making than male patients.

4.4.1.2 Patient age

Swenson et al., (2004) recruited 250 patients attending urgent care or general internal medicine clinics at a hospital. They were asked to watch two videos of a doctor and patient discussing the patient's use of complementary and alternative medicine. In one video the consultation was patient-centred, whereas in the other video it was more biomedical. They found that younger patients were more likely to prefer the patient-centred consultation than older patients (Swenson et al., 2004).

Similar results were reported by Street et al., (2003), who found that younger patients were more likely to prefer shared decision-making and an equal doctor-patient relationship, than older patients (R. L. Street et al., 2003). These results were also reported by Krupat et al., (2000) where younger patients preferred a more patient-centred approach to consultations (Krupat et al., 2000).

These studies suggest that younger patients prefer to be more involved in their consultations and healthcare, whereas older patients are more happy for doctors to take control over the decision-making process.

4.4.1.3 Patient ethnicity

The systematic review conducted by Schouten et al., (2006) outlined earlier, found that patients from ethnic minority backgrounds expressed fewer emotions and concerns, and were less assertive during consultations than white patients (Schouten & Meeuwesen, 2006).

Similar results were reported by Street et al., (2005), who found that ethnic minority patients asked fewer questions, expressed fewer concerns, and were less assertive in their consultations than white patients. Furthermore white patients were more likely to engage in these behaviours without prompting from the doctor, than patients from ethnic minority backgrounds (R. L. Street et al., 2005).

In contrast, Street et al., (2003) found no significant effect of patient's ethnicity on their tendency to ask questions, express concerns, or be assertive in the consultation (R. L. Street et al., 2003).

The findings regarding the effect of patient ethnicity on patient communication behaviours seems to be somewhat conflicting, however the majority of studies

suggest that patients from ethnic minority backgrounds tend to participate less actively in their consultations.

4.4.1.4 Patient SES

Previous studies have found several differences with regard to patient communication behaviours across the socioeconomic gradient, using various different indicators to measure SES.

The systematic review conducted by Verlinde et al., (2012) also looked at SES differences in patient communication behaviours, and found that low SES patients participated less actively in their consultations than high SES patients (Verlinde et al., 2012). However the majority of the studies included in the review focused on provider behaviours, with only a few studies looking at patient behaviours. Every single study reviewed measured provider behaviours in some way, however only 9 studies also measured patient behaviours.

During consultations breast cancer patients reporting low income or low levels of education tended to ask fewer questions and were less likely to volunteer information without prompting from the healthcare professional than high income or highly educated patients (Laura A Siminoff et al., 2006). Parents of paediatric patients with low educational attainment were less likely to express their opinion or emotions during their child's clinic appointment than more educated parents (R. L. Street, 1992). Low educated patients treated for breast abnormalities, rheumatoid arthritis or spinal disc herniation tended to express a lower preference for shared decision-making than more educated patients (Rademakers, Delnoij, Nijman, & de Boer, 2012).

A study was conducted in Scotland with 659 patients from 47 general practitioners in a number of areas with high or low deprivation levels as measured by SIMD. The results suggested that patients living in deprived areas had a significantly lower preference for shared decision-making and perceived that their GPs displayed less empathy. This predicted worse wellbeing and symptom severity (Mercer et al., 2016) While this study had a large sample size, it utilised a closed-response questionnaire which can be lacking in depth of information elicited.

A qualitative study was conducted in four different countries using focus group discussions. Participants were asked to watch videos of simulated consultations and to then discuss what they thought of the healthcare professional's performance. Participants with low levels of educational attainment participated significantly less in the discussions than their higher educated counterparts, and were more likely to refer to the affective aspect of the consultation, whereas the highly educated participants were more likely to refer to problem-focused aspects (Aelbrecht et al., 2015).

These studies suggest that low SES patients seem to participate less actively in their medical consultations, and have a lower preference for active participation than their higher SES counterparts.

4.5 Patient and doctor behaviours

In addition to the sociodemographic characteristics of both patients and physicians affecting the communication behaviours of both parties, studies have also found that patient communication behaviours affect doctor behaviours and vice versa; patients who ask more questions and express their opinion more often are more likely to be asked for their opinion and invited to ask questions, however patients were more

likely to engage in these behaviours if their physician involved them more in making decisions about their healthcare (R. L. Street, 1992; R. L. Street et al., 2005). This suggests that patient behaviours demonstrating a less active involvement in the consultation lead to less involving behaviours from the physician, which in turn make the patient feel less inclined to participate actively in the consultation (S. Willems et al., 2005).

However, a study has found that even when the influence of patient communicative behaviours was controlled for, family practice physicians gave more information to more educated patients than those with less education (R. L. Street, 1991). This suggests that despite the interactive effects of patient and provider communication behaviours, healthcare professionals still seem to be bringing some biases and stereotypes to their consultations, which may be contributing partly to SES differences in doctor-patient communication.

There are a number of studies which examine both patient communication behaviours and doctor communication behaviours, some of which have been described in previous sections (for example, Street et al., 2003, Street et al., 2007, Siminoff et al., 2006). However the majority of studies within the field of doctor-patient communication focus on doctor communication behaviours, while far fewer studies focus on patient communication behaviours. Those that do look at the patient's side of the medical encounter, also seem to only focus on a limited range of possible communication behaviours.

This, however, begs the question: what is the best communication style for patients and physicians to use within a consultation?

4.6 What is 'good' communication?

In more recent years there has been an emphasis on patient-centred care in healthcare settings, replacing the paternalistic style of communication which was once the norm. Paternalism in healthcare is characterised by the clinician making decisions for their patient, essentially taking control of the medical encounter while the patient has a more passive role (Cody, 2003). In contrast, patient-centred care emphasises eliciting patient's preferences and needs, so that they can make informed choices and be fully involved in decisions about their care (Levinson, Lesser, & Epstein, 2010). A patient-centred encounter is a partnership, rather than one individual dominating the discourse (Ronald M Epstein & Street JR, 2007). Some behaviours which are characteristic of patient-centred care are providing information, prompting the patient to ask questions and express opinions or preferences, and checking that the patient understands what has been said. It is also important that the patient participates actively in the consultation by asking questions and expressing opinions and any concerns (Ronald M Epstein & Street JR, 2007). This is represented in studies in the field of doctor-patient communication, which measure behaviours such as question asking, information provided, rapport building, and expression of opinions (Verlinde et al., 2012).

The term patient-centred care first made its appearance in 2001 in a report by the Institute of Medicine, which suggested six ways of improving the health care system. One such aim was to provide more patient-centred care, in other words, care which is responsive to the patient's needs and preferences with clinical decision-making being guided by the patient's values (Committee on Quality of Health Care in, Institute of, Iom, & National Academy of, 2001; King & Hoppe, 2013; Wolfe, 2001).

This has been adopted by NHS England who have committed to involving patients and carers more in their own treatment by empowering them to manage their health and make informed choices regarding treatment. This is supported by the NHS Five Year Forward View which was published in 2014, and recommends steps to facilitate the provision of patient-centred care. Patient-centred care has also been championed by various other organisations, including The King's Fund, The Health Foundation, and the Coalition for Collaborative Care.

The Care Quality Commission, which is an independent regulatory body of health and social care in England, currently has regulations regarding patient-centred care. The Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 9 states that healthcare providers must ensure that patients receive appropriate patient-centred care based on an assessment of their needs and preferences. While the Care Quality Commission cannot prosecute healthcare providers for breaching this regulation, they can take a number of measures in order to try and force improvement.

So various organisations endorse and try to enforce the provision of patient-centred care, but what are the benefits of this?

4.7 Benefits of good communication

A number of studies suggest that patient-centred communication has a beneficial effect for the patient. A randomised controlled trial conducted in Sweden with 199 acute coronary syndrome patients compared patients in a patient-centred care intervention group with those who were receiving usual care, in terms of a composite score measuring self-efficacy, physical activity levels, return to work, rehospitalisation and death. Level of patient education was also measured, dividing

patients into those who had secondary education or lower, and those who had higher than secondary education. Healthcare professionals treating patients in the intervention group attended a training course on patient-centred communication, and a health plan was developed with both the patient and their healthcare professionals to discuss their condition, resources, goals, barriers, and available support. It was found that more patients in the patient-centred care group showed an improvement in composite scores in comparison to those receiving normal care, and this difference was significant for patients with secondary education or less (Fors, Gyllensten, Swedberg, & Ekman, 2016). This suggests that patient-centred care is associated with improved health outcomes, particularly for low educated patients.

A prospective observational study conducted in Scotland examined the association between depression, deprivation and patient-centred care in 356 consultations with 25 GPs in deprived areas and 303 consultations with 20 GPs in affluent areas. Deprivation was measured using SIMD scores and depression was measured using the Patient Health Questionnaire 9 (PHQ-9). Patient perceived GP empathy was measured using the Consultation and Relational Empathy (CARE) measure. These were completed at the patient's appointment and again one month later. The appointments were video-recorded and then analysed using the Measure of Patient-Centred Communication and Mehrabian's Schemata. The results suggested that PHQ-9 scores indicative of depression were more common in deprived areas, and that perceived GP empathy and patient-centred communication were lower in deprived areas. Furthermore, patient-centred communication was predictive of higher PHQ-9 scores (Jani et al., 2012). One explanation is that patient-centred communication may be linked with improvements in symptoms of depression, but that patients from deprived areas may be less likely to receive a patient-centred

consultation. However inferences are limited because of the lack of a control group, and there may be only an association between symptoms of depression and patient-centred care. It may not necessarily be causative, as the effect may be the result of the stresses of living in (or close to) poverty. Also due to depression the patients may be engaging in behaviours which elicit fewer patient-centred behaviours from the doctor. Moreover, only a small section of each videoed appointment was analysed, rather than the entire tape. Some behaviours which would have changed the patient-centredness rating might have been missed because they fell outside of this small window.

Mead et al., (2002) conducted a systematic review of studies which examined the effect of patient-centred care in primary care settings on patient outcomes. Nine studies were included in the review, all of which measured patient-centredness using verbal coding schemes. However only one measured the doctor's nonverbal behaviour, and the majority of studies only looked at the doctor's communication behaviour, and not the patient's. They found that patient satisfaction was the most commonly studied outcome measure, although some studies found a positive association between satisfaction and patient-centred care while others reported no such association. Patient-centred care was linked with reduced levels of worry and patient perception of the consultation, although there was no significant association with patient enablement or health outcomes. There was, however, an association between the patient's perception of how patient-centred the consultation was, and their health status and healthcare utilisation (N. Mead & Bower, 2002). This suggests that the evidence regarding the benefits of patient-centred care is somewhat mixed, however it's important to note that most of the studies in this review did not examine patient communication behaviours. Therefore although the doctor may have been

engaging in patient-centred behaviours, we don't know if the patient was also engaging in such behaviours which are necessary for truly patient-centred care to take place (Ronald M Epstein & Street JR, 2007).

Stewart (1995) also conducted a systematic review of randomised controlled trials and observational studies which examined the effect of doctor-patient communication on patient outcomes. Their review included 21 studies, which were conducted in both outpatient and family practice settings. Most of the studies found a positive association between communication quality and patient outcomes, although a few found negative associations, or no association whatsoever. The outcomes which had a significant association were emotional wellbeing, whether the patient felt their reported problem had been resolved, physical functioning, pain, and some objective measures such as blood pressure and blood sugar levels (M. A. Stewart, 1995).

Pirhonen et al., (2017) conducted a randomised controlled trial at a hospital in Sweden with acute coronary syndrome patients. The intervention group comprised of 94 patients, while the control group had 105 patients. The control group received standard care for 6 months across inpatient, hospital-based outpatient, and primary care, while the intervention group received patient-centred care in the same settings for the same timeframe. The intervention group reported significantly greater self-efficacy than controls, and more of the intervention group had returned to work. The intervention group also reported greater increases in physical activity levels and better health-related quality of life, although these were not significant (Pirhonen, Olofsson, Fors, Ekman, & Bolin, 2017).

Kinmonth et al., (1998) also conducted a randomised controlled trial to examine the effect of patient-centred care on outcomes for type 2 diabetes patients in general practice. The study recruited 41 general practices in Wessex, England, 21 of which were in the intervention group and 20 were in the control group. The control group received standard care, while the nurses and GPs of the intervention group were given training on providing patient-centred care. After one year patients in the intervention group reported that their communication in the consultation was better, they were more satisfied with their care, and their overall wellbeing was significantly better than the control group. However, the intervention group lost less weight during the study period than the control group, and there were no significant differences in terms of lifestyle or glycaemic control (Kinmonth et al., 1998).

Bertakis et al., (2011b) conducted an observational study of 509 new patients attending outpatient services at a university medical centre in the USA, by analysing the patient-centredness of videotaped consultations with primary care physicians over the course of one year. They found that patients whose visits were rated as being more patient-centred had fewer specialist care appointments, fewer hospitalisations, less testing, and lower charges for medical services overall (Bertakis & Azari, 2011b). This suggests that patient-centred care is associated with lower utilisation of healthcare services, and thus lower medical expenses.

So the research seems to suggest that various aspects of patient-centred care are linked with numerous patient-reported outcomes and healthcare utilisation, however the evidence on objective health outcomes is somewhat mixed. Although it is important to note that many studies collect follow-up data after one year, at the most, which may be insufficient time for improvements in objective health outcomes to

manifest. An important question, though, is how do we measure these patient and doctor communication behaviours in consultations?

4.8 Measures of communication

There are a number of measures which have been used in research to quantify and analyse the doctor and patient behaviours within a consultation. These are typically either self-report or observational measures (Bertakis & Azari, 2011a).

4.8.1 Self-report measures

Self-report measures of doctor-patient communication are typically completed by either the patient, the doctor, or both parties. These measures focus on the individual's perception of communication behaviours which have taken place during a consultation, or their preferences for certain behaviours, for example whether they have been involved in decision-making regarding their care or to what extent they would like to be involved in such decisions.

While self-report measures can provide important information on patient's and doctor's preferences for communication style, when it comes to collecting data on the behaviours which were displayed in a consultation, there are a number of issues. Namely, that an individual's account of a consultation may not be entirely accurate, either due to misremembering certain details or social desirability bias motivating them to provide an inaccurate account.

4.8.2 Observational measures

In contrast, observational measures of doctor-patient communication are somewhat more objective than self-report measures. These involve the analysis of a consultation using a specific coding scheme, which states what behaviours and utterances to pick up on and how to classify them. This is usually done by one or

more researchers who are trained in that particular coding scheme, and allows for the quantification and statistical analysis of communication behaviours. Depending on the coding scheme, analysis is usually done with audio-recordings of consultations, although it can also be applied to video recordings if the coding scheme includes non-verbal as well as verbal behaviours.

There are various observational measures which have been developed for use in doctor-patient communication research over the years. In this section I will focus on two key measures: the Roter Interaction Analysis System (RIAS) and the Verona Coding Definitions of Emotional Sequences (VRCoDES).

4.8.2.1 Roter Interaction Analysis System (RIAS)

The Roter Interaction Analysis system (RIAS) quantifies both patient and doctor behaviours into task-oriented behaviours and socioemotional behaviours (D. Roter & Larson, 2002). There are 29 categories of task-oriented behaviour which mainly consist of asking questions, proving information, and conducting a physical examination, while there are 14 socioemotional categories which include empathy, request for or provision of reassurance, and laughing or joking (Sandvik et al., 2002).

This coding system can be applied directly to audio-recordings using the RIAS software, therefore transcription of recordings is not necessary for analysis to take place. This makes it much less time consuming, and also more practical for larger datasets. Furthermore, it is relatively easy to learn and become proficient in RIAS coding (D. Roter & Larson, 2002).

RIAS has been used to analyse communication in many studies across a variety of settings, including podiatry, oncology, gynaecology, primary care, emergency care, and end of life. It has also been used across the USA, Europe, Asia, Africa, and

South America, and has been translated into various European languages (D. Roter & Larson, 2002).

Studies have found that the RIAS has an average reliability of 0.85 based on Pearson correlation coefficients, and it can be adapted for coding encounters with more than two speakers, for example if a patient's friend or family member sits in on the consultation or another healthcare professional is in attendance (D. Roter & Larson, 2002).

However, one criticism of RIAS is that it merely analyses the type and frequency of behaviours, and not the sequence which they occur in. It allows the coder to analyse how many times patients ask questions and how many times doctors give certain responses, and vice versa, but it does not tell us what answers were given in response to what questions (Sandvik et al., 2002). Roter et al., (2002) have responded to this criticism, stating that RIAS does allow for the collection of sequence data but that it is rarely analysed and published because it is difficult to work with (D. Roter & Larson, 2002).

4.8.2.2 Verona Coding Definitions of Emotional Sequences (VRCoDES)

The Verona Coding Definitions of Emotional Sequences (VRCoDES) is a method of quantifying doctor-patient communication through patient's expression of concerns and healthcare professionals' responses to these expressions in medical consultations (Piccolo et al., 2017). It differs from RIAS, in that it focuses on patient's expression of emotions during consultations as opposed to other types of communication behaviours. Furthermore, it explicitly examines sequences within an interaction, recording how the doctor responds to each emotional expression from a patient.

However, like RIAS no transcription is necessary as analysis can be done directly onto audio-recordings using specialist software.

Patient cues and concerns

When analysing a patient's role in the conversation, first each utterance is classed as either a cue or concern. A cue is defined as a verbal or nonverbal hint that suggests an unpleasant emotion, whereas a concern is a clear expression of emotion which is explicitly verbalised and stated as being important to the patient. If a cue has been expressed, then the type of cue is identified e.g. nonverbal cue (such as crying), use of vague words to describe emotions, etc. Then each cue or concern is classed as either patient-elicited (unprompted by the clinician) or healthcare provider elicited (prompted by the clinician).

Healthcare professional responses

When analysing a clinician's role in the conversation only their responses to patient cues or concerns are coded. Firstly each response is either coded as explicitly referring to the patient's cue or concern, or non-explicitly referring to it in a vague way. Then each response is coded as either providing space for the patient to talk about the topic or emotion more, or reducing space so that the patient has less opportunity to discuss that topic. Finally each response can be coded as a specific behaviour e.g. ignoring the cue/concern, acknowledging, actively inviting the patient to discuss it further, etc. In addition, the number of cues/concerns per 'turn' in the conversation can be recorded so that the response can be matched to each cue/concern on occasions when more than one cue/concern is expressed. This measure allows the researcher to compare the frequency of cues, concerns, types of cue, and types of clinician response between different groups.

The VRCoDES has been found to be reliable both when measuring patient's concerns (inter-rater agreement – 81.46%; Cohen's Kappa=0.7, $p<.0001$) (Zimmermann et al., 2011), and healthcare professional's responses (inter-rater agreement – 92.9%; Cohen's Kappa=0.9, $p<.0001$) (Del Piccolo et al., 2011).

Since its publication in 2011, this measure has been used in various countries, in a number of different settings with different patient groups, such as general practice (Butalid, Verhaak, van Dulmen, & Bensing, 2014; Zhou, Lundy, et al., 2015), psychiatry (Del Piccolo, Mazzi, Goss, Rimondini, & Zimmermann, 2012), outpatient pain clinics (Eide, Eide, Rustoen, & Finset, 2011), cancer clinics (Finset, Heyn, & Ruland, 2013; Zhou, Humphris, et al., 2015), dentistry (Zhou et al., 2014), OSCE consultations (Zhou, Collinson, Laidlaw, & Humphris, 2013), radiotherapy (L. Barracliffe, Yang, Cameron, Bedi, & Humphris, 2018), home care visits (Hoglander, Eklund, Eide, Holmstrom, & Sundler, 2017), and veterinary clinics (Vijfhuizen, Bok, Matthew, Del Piccolo, & McArthur, 2017).

Del Piccolo (2017) has made the case that the cues and concerns measured by the coding scheme match up with the emotional aspects of patient-centred care such as providing space for the patient to speak and demonstrating an interest in what the patient has to say (Del Piccolo, 2017). This suggests that it could be a useful tool for measuring certain elements of patient-centred care, especially if sequential analysis is of interest.

So there are measures available to quantify doctor-patient communication, but what if we want to try and improve communication within a consultation?

4.9 Interventions

Within the field of doctor-patient communication various studies have formulated and tested interventions which are designed to improve various aspects of the doctor-patient relationship. Some focus on patient behaviours, some on doctor behaviours, and some interventions aim to improve both patient and doctor behaviours.

4.9.1 Provider focused

Most communication skills interventions aimed at doctors tend to take the form of a training course, which can take place either face to face or online. These tend to differ in terms of the strategies used, duration of the course, and whether it is an individual or group intervention.

Berkhof et al., (2011) conducted a systematic review of systematic reviews on interventions designed to improve physicians' communication skills. Twelve systematic reviews were included, which found that interventions included the use of patient feedback, role-play, modelling of good communication behaviours, discussion, written information, and presentations. These took the form of either individual or group sessions, and the most effective interventions lasted for at least one day, with one review stating that interventions lasting three days or more were most effective. The most effective interventions combined instruction with practical exercises, so that physicians could practice newly learned skills. The most effective strategies in terms of improving physician communication behaviours and patient satisfaction ratings were patient feedback and role-play with real or simulated patients (Berkhof, van Rijssen, Schellart, Anema, & van der Beek, 2011).

4.9.2 Patient focused

Communication skills training for patients also frequently takes the form of training courses, although this tends to be either through the provision of written information or face to face teaching. These also vary in terms of strategies and duration.

D'Agostino et al., (2017) conducted a systematic review of interventions designed to improve patient's communication skills. They included 38 articles reporting the results of 32 studies, and found that 13 of these interventions simply consisted of providing participants with workbooks, leaflets, videos, or computer-based resources. An additional 13 interventions provided these materials in conjunction with one to one coaching, and only six interventions consisted of group workshops or courses. Half of the interventions lasted an hour or less, with only six interventions lasting longer. Interventions which targeted patients' expression of concerns during consultations were the most effective, in comparison to those which targeted other patient behaviours such as question asking and stating preferences. Brief and self-paced interventions were found to be effective in improving patient communication behaviours, and the addition of practical exercises did not seem to significantly improve the efficacy of an intervention (D'Agostino et al., 2017).

Harrington et al., (2004) also conducted a systematic review of interventions designed to improve patient participation in consultations. They included 25 papers, and found that most interventions simply provided written materials, with the second most common intervention design being face to face coaching and videotapes. Only a few studies combined both strategies. The duration of interventions ranged from 10 minutes to two hours, and half of the interventions produced a significant improvement in patient participation (Harrington, Noble, & Newman, 2004).

Cegala et al., (2000) developed an intervention designed to improve patients' information-seeking and information-provision behaviours in family practice appointments. The intervention consisted of a workbook which was posted to 50 patients 2 - 3 days before their appointment. It contained examples of desired communication behaviours, and prompted patients to write down questions to ask during the appointment, as well as list their symptoms and medical history. The control group contained 51 patients and simply received standard care, while a third group of 49 patients received a brief summary of the information contained in the workbook while in the waiting room immediately prior to their appointment. They found that patients in the intervention group asked more questions and provided more detailed information during the consultations than the other two groups (Cegala, McClure, Marinelli, & Post, 2000).

4.9.3 Patient and provider focused

In contrast to communication skills interventions which focus purely on patient training or doctor training, there are relatively few interventions which target both patients and doctors.

Schoenthaler et al., (2014) conducted a systematic review of the effect of communication training on cardiovascular-related clinical outcomes. They included 15 papers, seven of which described interventions focusing on patients, seven focused on doctors, and only one intervention targeted both patients and doctors. The intervention targeting both parties did not produce a significant improvement in physician behaviour, but did result in greater involvement in decision-making for patients (Schoenthaler, Kalet, Nicholson, & Lipkin, 2014).

The systematic review by D'Agostino et al., (2017) found that only eight out of 32 interventions aimed at patient communication behaviours, also included training for physicians. However it does not report the efficacy of such interventions.

The systematic review by Harrington et al., (2004) also found that only 2 out of 25 interventions aimed at patient participation behaviours, also included some form of training for physicians.

4.9.3.1 Holistic Needs Assessments (HNAs)

In contrast to typical training courses for both patients and physicians, Holistic Needs Assessments (HNAs) might be considered to be an intervention which improves doctor-patient communication and is aimed at both parties. HNAs are question prompt lists which list a variety of potential issues and concerns. This allows the patient to select what issues they wish to discuss during their appointment. HNAs are typically given to patients while in the waiting room for their appointment, and their responses are given to the doctor who their appointment is with. This is designed to facilitate patients' expression of concerns, and make it easier for doctors to respond to these concerns.

Various HNAs have been developed by different researchers and organisations, and have been tailored for different patient groups. For this section I will focus on one specific HNA: The Patient Concerns Inventory.

The Patient Concerns Inventory (PCI)

Development

The Patient Concerns Inventory (PCI) was designed to facilitate discussion between patients and healthcare professionals during appointments to ensure that needs are met which the patient might find difficult to bring up during clinical encounters (S.

N. Rogers & Lowe, 2014). The PCI can be used to determine which concerns the patient wishes to raise during their consultation. This was developed by Professor Simon Rogers in 2007 and trialled in one head and neck cancer clinic at Aintree Hospital in the UK. The PCI has been adapted for a number of conditions including neuro-oncology, breast cancer and rheumatology, although it was originally developed for head and neck cancer.

Current use

Currently the PCI developed for head and neck cancer (PCI-HN) is still only being used in Professor Rogers' head and neck oncology review clinic at Aintree Hospital (Kanatas, Humphris, Lowe, & Rogers, 2015), although a study of the PCI has been carried out with head and neck cancer patients from oral and maxillofacial clinics at seven hospitals in Malaysia (Hatta, Doss, & Rogers, 2014).

What is the PCI and how is it used?

The PCI-HN is a 56-item question prompt list of concerns specific to head and neck cancer patients, ranging from physical, treatment-related, social-care, and psychological, as well as a section to indicate any specific professionals or support staff the patient may wish to speak to (S. N. Rogers & Lowe, 2014). The concerns are split into five domains: Physical and functional, Psychological and emotional or spiritual wellbeing, Social care and wellbeing, Treatment-related, and Other. These domains were developed and applied to the existing list of concerns using a Delphi approach with ten head and neck cancer experts (Ghazali, Roe, Lowe, & Rogers, 2015). The University of Washington Quality of Life (UW-QoL) is a questionnaire consisting of 12 domains specific to head and neck cancer, with each domain being scaled from 0 to 100 (where lower scores indicate a worse QoL). There is also a question which asks the patient to highlight the 3 areas which have been most

important to them in the previous week (Kanatas, Ghazali, Lowe, & Rogers, 2012). These two measures are used together in Professor Rogers' clinic to give the clinician a better picture of any concerns which the patient may be experiencing, and are given to patients while they are waiting for their head and neck oncology review appointment with the consultant. This is completed in a separate room off of the waiting area, where a volunteer is on hand to assist the patient in completing the forms, and the completed forms are then sent to the consultant for use in the patient's appointment.

Previous PCI studies

The PCI has not been found to significantly increase the number of referrals from clinic appointments in general, although the number of referrals to oral rehabilitation and psychological support services increased (Ghazali et al., 2011). Recent studies have found that the use of the PCI is feasible with elderly patients and those who have a low level of education (Hatta et al., 2014; S. N. Rogers, Audisio, & Lowe, 2015), suggesting that the PCI may be suitable for use with low SES patients.

When asked about use of the PCI, patients have stated that it made the consultation feel more personal and straight to the point, as well as reminding them about questions they wished to ask (S. N. Rogers, El-Sheikha, & Lowe, 2009). One study found that most patients stated that the PCI was easy to use and that they would like to use the PCI again, however a few patients did not wish to use it again (S. N. Rogers & Lowe, 2014).

It has also been found that the number of concerns selected on the PCI can be predictive of patient-reported quality of life, suggesting that it may be a useful screening tool to improve care and resource management (S. N. Rogers, Lowe, & Kanatas, 2016). A recent study also found that the PCI could potentially be used to

identify patients who may be distressed or at risk of being significantly distressed, however it also found that consultations were longer when more concerns were selected (Ghazali et al., 2017).

Currently a trial is being conducted in Liverpool and Leeds hospitals to determine whether long-term use of the PCI might improve patients' quality of life (S. Rogers et al., 2019), although there have not yet been any studies which have examined whether the PCI affects the doctor and patient communication behaviours within the consultation.

A recent narrative review compared the PCI with other HNAs used in oncology, finding that most HNAs were for cancer sufferers in general and were not tailored to specific types of cancer, unlike the PCI (Miller & Rogers, 2018).

4.10 Aims and research questions

The previous research outlined in chapters 2, 3, and 4 suggests socioeconomic inequalities in risk of developing head and neck cancer and post-treatment quality of life, as well as SES differences in communication between patients and clinicians. Therefore the main focus of the PhD was to explore how and why SES influenced doctor-patient communication in head and neck cancer consultations, with a specific focus on patient participation behaviours.

The PhD consisted of four studies, the results of which informed the design and aims of each subsequent study.

4.10.1 Study 1 – Chapter 5

Given that previous systematic reviews had focused on clinician behaviours within interactions, I decided to start by conducting a systematic mapping review of studies exploring SES differences in patient participation behaviours. This was in order to

map the current literature in this field and inform the aims and design of subsequent studies for the PhD.

Research question: What research has been done to explore why does the tendency to and desire for patient participation behaviours in healthcare consultations with doctors vary according to SES and what aspects of SES have been explored?

Aim:

- To map the characteristics of published studies which provide data on the link between patient participation behaviours and socioeconomic status.

4.10.2 Study 2 – Chapter 6

The results of the systematic mapping review highlighted a lack of UK-based patient participation research with head and neck cancer patients, as well as few studies which looked at the patient participation behaviour of raising concerns, or measured SES using area-level deprivation. Therefore for the next study I decided to examine whether raising of concerns differed by IMD status in head and neck cancer consultations.

Research question: Do PCI responses differ across the socioeconomic gradient in patients attending routine oral cancer follow-up clinics, and how do they differ?

Aim:

- To examine whether the number and type of PCI items selected for head and neck consultations significantly differ by patients' IMD status.

4.10.3 Study 3 – Chapter 7

Study 2 found no significant associations between area-level deprivation and raising of concerns during head and neck cancer consultations using the PCI. However the

consultations themselves had not been analysed, raising the possibility that patients may have raised concerns even if they had not selected items using the PCI. Therefore for this study I examined whether raising of concerns differed by IMD status, through the VRCoDES analysis of consultations.

Research question: Does the number of concerns raised during head and neck cancer consultations significantly differ depending on the patient's IMD status?

Aim:

- To examine whether the number and type of concerns raised during head and neck cancer consultations significantly differ by the patient's IMD status.

4.10.4 Study 4 – Chapter 8

The results of study 3 found no significant association between the number and type of concerns raised during head and neck cancer consultations and patient IMD status, suggesting that the link between SES and patient participation behaviours may be more complex than originally thought. Therefore for my final study I decided to qualitatively explore the doctor-patient interaction in more depth, using a variety of SES measures and patient participation behaviours.

Research question: How and why does the doctor-patient interaction differ by patient SES in head and neck cancer consultations?

Aims:

- To explore the preferred and experienced patient participation behaviours of individuals diagnosed with head and neck cancer, and how and why these differ by SES.

- To qualitatively analyse SES differences in the observed interactions which take place during head and neck cancer follow-up appointments.
- To explore which aspects of SES appear to be important in influencing the doctor-patient interaction.

Chapter 5: Socio-economic differences in patient participation behaviours in doctor-patient interactions - a systematic mapping review of the literature

5.1 Introduction

Two systematic reviews of quantitative studies have been conducted on SES differences in doctor-patient communication, including patient participation in healthcare appointments. These were conducted by Verlinde et al., (2012) and Willems et al., (2005). The most recent of these, by Verlinde et al. (2012) identified 20 papers and measured SES using the "social class related concepts" of education, income, and occupation. Confusingly, three of the studies included in this review measured SES using 'social class', although they did not specify exactly how this was defined. Of the 20 included papers, all focused on clinician behaviours while only 11 papers also looked at patient behaviours. The authors found that low SES patients tended to participate less actively in their consultations, by asking fewer questions, being less likely to express their opinions or emotions, expressing a lower preference for shared decision-making, and being less likely to volunteer information unprompted than their high SES counterparts (Verlinde et al., 2012). Furthermore, low SES patients were approached in a more directive manner by clinicians: spending less time building rapport, being less likely to give advice or discuss cancer screening, and being less likely to listen to them than high SES patients (Verlinde et al., 2012).

While there does not seem to be a standard definition of patient participation (Richard, Glaser, & Lussier, 2017), most studies focus on behaviours which are deemed as intrinsic to patient-centred care, such as question asking, raising concerns, and expressing opinions, preferences and emotions (Ronald M Epstein & Street JR, 2007). This is reflected in the findings of the Verlinde et al. (2012) systematic review

described above. For example, Siminoff (2006) examined rapport building, question asking and volunteering information without prompting in a sample of breast cancer patients (Laura A Siminoff et al., 2006). Street (1992) looked at expression of opinions and emotions by parents of paediatric patients (R. L. Street, 1992).

Verlinde et al's (2012) systematic review examined both patients' tendencies to participate as well as their desire to participate in clinical consultations. However since the focus of the review was on doctor-patient communication in general, the search criteria were not specific to various aspects of patient participation behaviour and therefore the review may not have been sensitive enough to identify whether certain patient participation behaviours had been more researched then others. All systematic reviews must find an appropriate balance between the sensitivity of a search and how manageable it is with the resources available ("Institute of Medicine (IOM) IOM Standards for Systematic Reviews: Standard 3.1: Conduct a comprehensive systematic search for evidence.," 2011).

Furthermore the Verlinde et al. (2012) review's scope was limited to studies which measured SES using education level, income, occupation, or social class. However there are several other SES indicators such as health insurance status, receipt of benefits, or area-level deprivation, which may not have been captured yet may still be important.

This was an update of the systematic review conducted by Willems et al., (2005) on SES differences in doctor-patient communication, which included 12 papers. Again, all of these papers examined doctor behaviours, while only 3 looked at patient behaviours (S. Willems et al., 2005). Differences in patient participation has been previously identified as an important way in which patients from different

socioeconomic backgrounds differ in healthcare communication (Mercer et al., 2016; Rademakers et al., 2012; Laura A Siminoff et al., 2006; R. L. Street, 1992). Again, because the study by Willems et al. (2005) focused on SES and doctor-patient communication in general, we do not know if there is relatively little literature on the patient participation aspects or whether the work by Verlinde et al. (2012) and Willems et al. (2005) was insufficiently specific to reveal it.

Based on these factors I decided to carry out a systematic mapping review of studies which examined patient participation behaviours in doctor-patient interactions in relation to a wider variety of measures of SES. I defined patient participation behaviours to consist of question asking, raising concerns, involvement in decision-making, rapport building, and expression of opinions, preferences and emotions.

I chose to conduct a systematic mapping review, as such reviews are useful for detecting patterns in a large body of literature in order to identify areas for future research. As such, details of the included studies are summarised without quality assessment or presenting statistical analyses (Grant & Booth, 2009; "Institute of Medicine (IOM) IOM Standards for Systematic Reviews: Standard 3.1: Conduct a comprehensive systematic search for evidence.," 2011). Furthermore, I did not have sufficient time or resources to conduct a full systematic review.

5.2 Methods

My review question was: What research has been done to explore why does the tendency to and desire for patient participation behaviours in healthcare consultations with doctors vary according to SES and what aspects of SES have been explored?

Aim:

- To map the characteristics of published studies which provide data on the link between patient participation behaviours and socioeconomic status.

An initial broad search in Medline was run to help identify relevant electronic search terms and the likely size of the review. At this stage I found that including screening appointments and emergency admissions made the scope of the review far too broad and unmanageable, therefore I decided to introduce limits in the electronic search terms regarding ongoing doctor-patient relationships. Following this, search terms were grouped by whether they related to socioeconomic status or doctor-patient communication, and run with the guidance of an information specialist at the university. Several versions of the search strategy were run, some of which produced too few results (225) and some did not appear to pick up the relevant papers. This was done until my search strategy was refined in order to produce a sufficient number of suitable results. The strategy was then altered as necessary for searching the other databases, and the results of the searches were combined. However based on the large number of results even after deduplication (10,329) it was determined that a mistake had been made when altering the search for other databases. This was redone and the searches were ran again, producing a more appropriate number of results following deduplication, indicating that the problem had been solved.

The Verlinde et al., (2012) review only included quantitative studies, however, given my research question I did not wish to restrict by study type so that I could adequately map the literature in the field of SES differences in patient participation. Therefore both qualitative, quantitative and mixed methods studies were also included in my review.

Since health system reimbursement and provider cultural characteristics have been shown to influence patient participation (Ayonrinde, 2003; Peluso et al., 2018; Slowther, Hundt, Purkis, & Taylor, 2012), I restricted the review to systems in 'developed' countries as defined by the OECD's Development Assistance Committee list of Official Development Assistance recipients. This was to facilitate comparison with the results of the other studies conducted as part of this PhD, which were also undertaken in this context. This is because such countries are low or middle income according to the World Bank, or Least Developed Countries according to the United Nations, and are therefore likely to have a very different healthcare system from the UK, as well as very different socioeconomic inequalities in healthcare.

Furthermore, only studies looking at appointments with doctors were included to ensure the review was manageable and the literature could be adequately summarised. As has been mentioned in Chapter 4, section 4.3., previous studies have found significant differences in communication styles and behaviours between doctors and with other professionals, e.g. nurses, physiotherapists, psychologists, etc. For example, nurses seem to spend more time building rapport with patients and have longer appointments in general than doctors (H Sandhu et al., 2009; Vinall-Collier et al., 2016).

Prior to commencement of the review a protocol was written, which can be found in Appendix 8.

5.2.1 Electronic searching

An electronic search was undertaken of the following databases: Medline, CINAHL, PsychINFO, and Web of Science. Literature was searched from 1980 to 2018 since

prior to 1980 there was much less electronic indexing. The search strategy contained free text and subject headings such as patient-centred care, question asking, raising concerns, involvement in decision-making, building rapport, expression of preferences, emotions or opinions, educational status, income, occupational status, employment, social class, and socioeconomic factors. This was modified as necessary for each database. A full copy of the electronic search tailored for Medline is given in Appendix 1. Backwards and forwards citation chasing and hand searching of journals was not conducted for this mapping review. This was because I wished to look for patterns in the literature without exhausting it, and also due to limited time and resources available to me.

Inclusion criteria for the review were:

- Studies involving patient perspectives on actual and desired question asking, raising concerns, involvement in decision-making, rapport building, or expression of opinions, preferences and emotions.
- SES gradient measured in the form of education, income, occupation, or 'other measures' which included patients' health insurance status, income indicators of state benefits, and area-based measures relating to the patients' home address
- Published in 1980 onwards
- Studies involving adult patients
- Only studies which focused on doctor-patient interactions
- Written in English language only

Studies were excluded if:

- They included only healthcare professional perspectives on patient participation
- Patients under 18 or parents of patients only were recruited
- The study concerned adult patient perspectives of childhood experiences
- The study was conducted in a country on the OECDs Development Assistance Committee list of Official Development Assistance recipients ("OECD DAC list of ODA recipients," 2018). This was in order to limit literature to higher income countries where the healthcare systems were likely to be similar.
- The appointment involved emergency attendances or screening
- The interactions were with healthcare professionals who were not medical doctors
- They were opinion articles
- They were systematic reviews

5.2.2 Study selection

One reviewer (SA) screened all titles and abstracts for selection and to remove duplicates, with a second reviewer only screening 1 in 5 (885) titles and abstracts. Both reviewers then independently screened the full texts for inclusion in the study, and any disagreements were resolved through discussion with two independent reviewers. A second reviewer screened 1 in 5 (73) full papers against inclusion criteria. The two reviewers disagreed on 11 full papers, which were discussed with the independent reviewers. Following this, 7 papers were excluded.

5.2.3 Data extraction

Both reviewers extracted data from the included studies using a standardised extraction form, and disagreements were resolved in the same manner as before. The following information was obtained during data extraction: year published, country the study was conducted in, study method and design, population recruited, study setting, sample size, how SES is measured, what patient participation behaviours are reported, and key results. Endnote was used to manage references throughout screening of titles and abstracts, as well as data extraction.

5.2.4 Data analysis

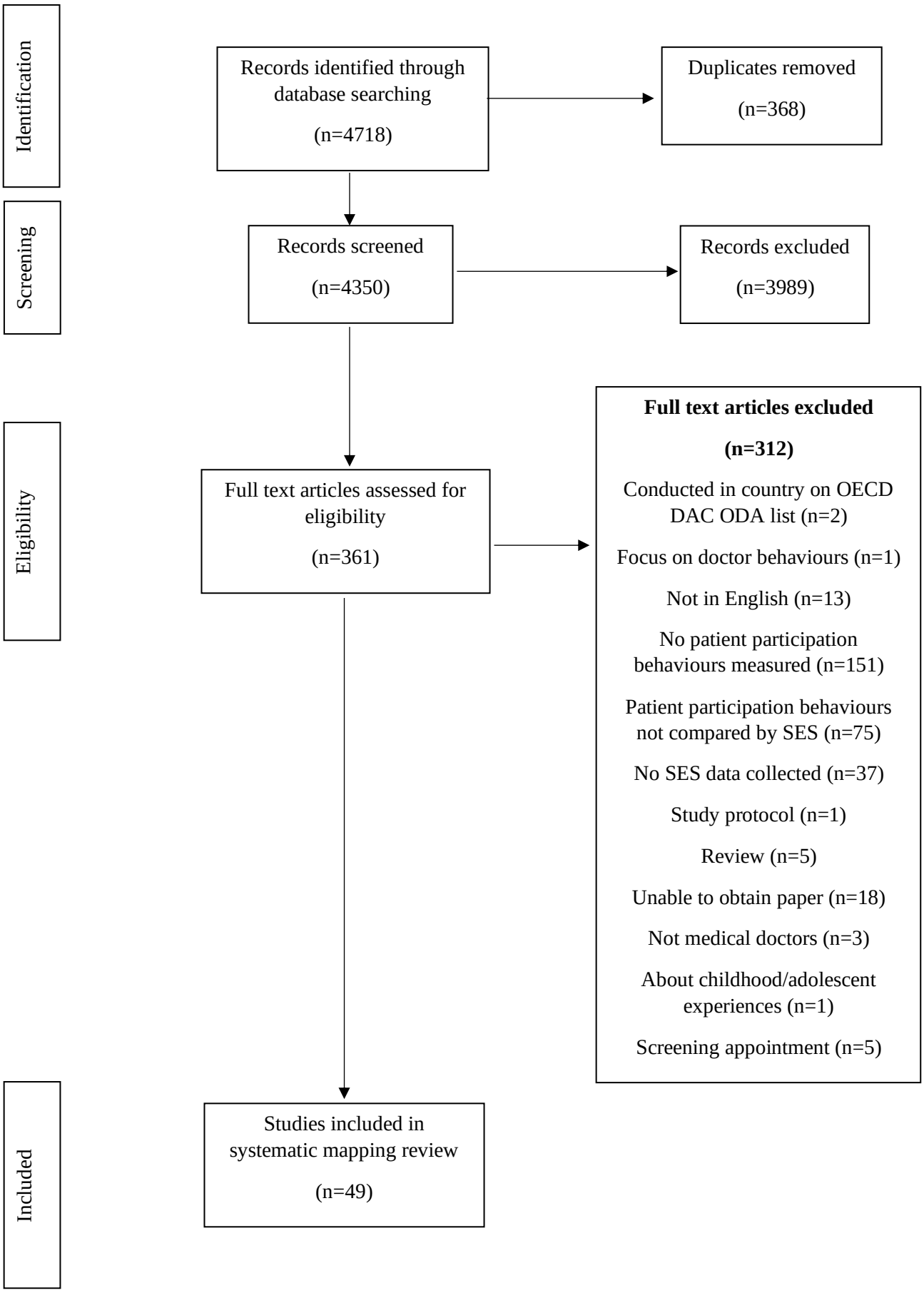
The aim of the review as to investigate what research had been done into how patient participation behaviours in doctor-patient interactions is related to differences in a wide range of possible various measures of socio-economic status. Therefore the data analysis plan was to a) quantify how many studies of various types of study designs (not confined to RCTs) had been done in this area; what type of study designs were the most common, and what the settings for these studies were (e.g. which countries, whether in primary, secondary or tertiary care); what type of participants the studies involved (e.g. cancer patients or other conditions); b) what type of patient participation behaviour had been studied (e.g. rapport building and/or other aspects); and c) identify what types of SES indicators had been used in the various studies and the direction of any reported associations between SES and patient participation behaviours.

5.3 Results

After searching electronic databases, 4718 articles were identified. The titles and abstracts of these were imported into Endnote and 368 duplicates were removed. Of the remaining 4350 entries, 3989 articles were excluded, leaving 361 entries. After

screening the full texts of all 361 articles, there was disagreement between the two reviewers on 11 papers. Following discussion, 7 of these papers were excluded. After screening, 49 studies were included in the review. The PRISMA diagram can be found in Figure 5.1.

Figure 5.1. PRISMA diagram



The characteristics of the 49 included studies can be found in Table 5.1. The majority of the included studies (79.6%, *n* = 39) were published in the last 10 years, with only 10 being published before 2008. Of those published in the last 10 years, 24 papers were published after 2012. None of the included studies were published before 2000 (Fig. 5.2). Only 3 studies were conducted in the UK, none of which recruited cancer patients, while the majority of studies had been conducted in the USA (46.9%, *n* = 23). The second most common country was the Netherlands (10.2%, *n* = 5), with only 3 studies conducted in Australia. 'Other' countries included Spain, Estonia, Germany, Norway, and Finland (Fig. 5.3).

Figure 5.2. Number of studies published by year

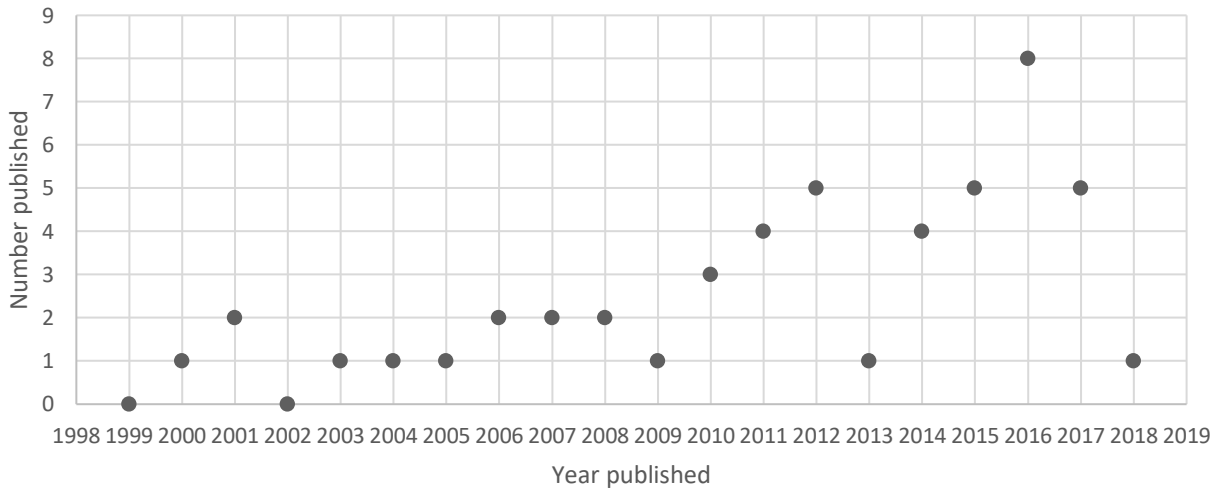


Figure 5.3. Countries the included studies were conducted in

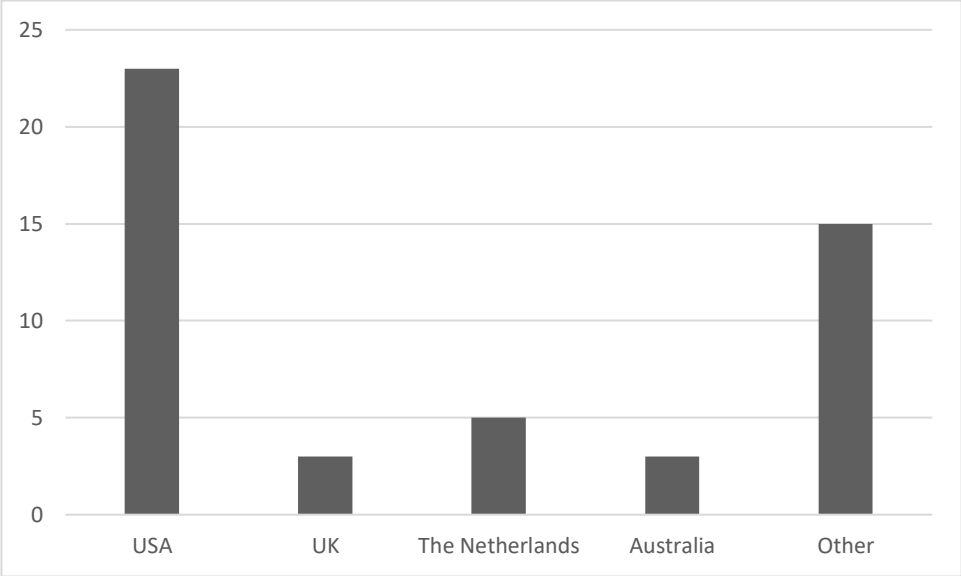


Table 5.1. Characteristics of included studies

Author	Country	Study population	Methods	Number of participants	SES measure	Patient participation behaviours measured	Direction of association
1. Aasen et al, (2012) (Aasen, Kvangarsnes, & Heggen, 2012)	Norway	End stage renal disease patients	Qualitative interviews	11	Education	Involvement in decision making, question asking, and expression of opinions	No statistical analyses performed
2. Ackermans et al, (2018) (Ackermans et al., 2018)	The Netherlands	Patients with osteoarthritis of the hip or knee	Questionnaire	142	Education and employment	Involvement in decision making, and expression of opinions, preferences and emotions	No associations
3. Adams et al, (2001) (Adams, Smith, & Ruffin, 2001)	Australia	Asthma patients	Questionnaire	128	Income, education, employment, receipt of benefits, and housing situation	Involvement in decision making	Positive association with education only
4. AlHaqwi et al, (2015) (AlHaqwi et al., 2015)	Saudi Arabia	Adult family practice patients	Questionnaire	236	Education	Involvement in decision making	Positive association
5. Aro et al, (2012) (Aro, Pietila, & Vehvilainen-Julkunen, 2012)	Estonia	Adult ICU patients	Questionnaire	166	Education	Involvement in decision making	Negative association

6. Arora et al, (2000) (Arora & McHorney, 2000)	USA	Hypertension, diabetes, congestive heart failure, myocardial infarction, and clinical depression patients	Questionnaire	2197	Education, income and employment	Involvement in decision making	Positive association with education only
7. Attanasio et al, (2015) (Attanasio & Kozhimannil, 2015)	USA	Women aged 18-45 who gave birth in US hospitals	Questionnaire	2400	Education and insurance	Question asking	Positive association for education Negative association for insurance type
8. Beauchamp et al, (2015) (Beauchamp et al., 2015)	Australia	Patients attending chronic disease services	Questionnaire	813	Insurance and education	Involvement in decision making	No associations
9. Bell et al, (2001) (Bell, Kravitz, Thom, Krupat, & Azari, 2001)	USA	Patients reporting a new or worsening problem, or worries about serious illness	Questionnaire	909	Education, employment, income and insurance	Raising concerns	No association for education and income only, other SES variables not analysed
10. Bozec et al, (2016) (Bozec et al., 2016)	France	Head and neck squamous cell carcinoma patients	Questionnaire	200	Education and occupation	Expression of preferences	No associations

11. Chung et al, (2012) (Chung, Lawrence, Curlin, Arora, & Meltzer, 2012)	USA	Patients admitted to a general internal medicine service	Questionnaire	8308	Education	Involvement in decision making and expression of preferences	Positive association for involvement in decision making only
12. Cohen et al, (2013) (M. Z. Cohen, Jenkins, Holston, & Carlson, 2013)	USA	Patients admitted to hospital for hematopoietic stem cell transplantation	Longitudinal qualitative interviews	60	Education and occupation	Involvement in decision making	No statistical analyses performed
13. Dang et al, (2017) (Dang, Westbrook, Njue, & Giordano, 2017)	USA	New patients attending a HIV clinic	Longitudinal qualitative interviews	21	Occupation	Question asking and involvement in decision making	No statistical analyses performed
14. De las Cuevas et al, (2014) (De las Cuevas & Penate, 2014)	Spain	Outpatient psychiatric patients	Questionnaire	846	Education	Involvement in decision making	No associations
15. Deen et al, (2011) (Deen, Lu, Rothstein, Santana, & Gold, 2011)	USA	Community health centre patients	Intervention-pilot study	252	Education	Involvement in decision making	No associations
16. Durand et al, (2016) (Durand et al., 2016)	UK	Chronic kidney disease patients	Questionnaire	492	Education	Involvement in decision making	No associations
17. Ellington et al, (2006) (Ellington, Wahab, Martin, Field, & Mooney, 2006)	USA	General population (some had cancer)	Focus groups	55	Education and employment	Involvement in decision making and expression of preferences	No statistical analyses performed
18. Friis et al, (2016) (Friis,	Denmark	Patients with diabetes,	Questionnaire	29,473	Education	Question asking, raising concerns,	Positive associations

Lasgaard, Osborne, & Maindal, 2016)		cardiovascular disease, COPD, musculoskeletal disorders, cancer, or mental disorders				and expression of opinions, preferences and emotions	
19. Garfield et al, (2007) (Garfield, Smith, Francis, & Chalmers, 2007)	UK	Patients with type 2 diabetes or rheumatoid arthritis	Questionnaire	516	Social class (composite measure)	Involvement in decision making	Positive associations
20. Gleason et al, (2016) (Gleason, Tanner, Boyd, Saczynski, & Szanton, 2016)	USA	Older adults with hypertension, arthritis, cholesterol, diabetes, cancer, heart disease or depression	Questionnaire	277	Education, financial strain, and finances at the end of the month	Involvement in decision making	No significant associations
21. Henselmans et al, (2015) (Henselmans, Heijmans, Rademakers, & van Dulmen, 2015)	The Netherlands	Patients diagnosed with a somatic chronic disease	Questionnaire	1314	Education	Involvement in decision making, question asking, and expression of opinions, preferences and emotions	No significant associations
22. Jacobs-Lawson et al, (2009) (Jacobs-Lawson, Schumacher, Hughes, & Arnold, 2009)	USA	Lung cancer patients	Questionnaire	100	Income and education	Involvement in decision making and expression of preferences	No significant associations for education only, income not entered into analysis
23. Janz et al, (2004) (Janz et al., 2004)	USA	Breast cancer patients	Questionnaire	101	Education, employment and income	Involvement in decision making, question asking,	Positive association between

						raising concerns, and expression of opinions, preferences and emotions	education and involvement in decision making only No significant associations for income and employment, and other participation behaviours not entered into analysis
24. Jonsdottir et al, (2016) (Jonsdottir, Gunnarsdottir, Oskarsson, & Jonsdottir, 2016)	Iceland	Patients who reported and consulted for chronic pain	Questionnaire	754	Education and income	Involvement in decision making	No significant associations
25. Lu et al, (2011) (Lu, Shaw, & Gustafson, 2011)	USA	Underserved women newly diagnosed with breast cancer	Intervention-pilot study	231	Education	Involvement in decision making, question asking, and raising concerns	Positive association for question asking only No significant associations for other variables
26. Lubetkin et al, (2010) (Lubetkin, Lu, & Gold, 2010)	USA	Patients attending urban health centres	Questionnaire	454	Education	Involvement in decision making	Positive association

27. Magnezi et al, (2015) (Magnezi, Bergman, & Urowitz, 2015)	Israel	General population	Questionnaire	508	Education and income	Involvement in decision making, rapport building, and expression of preferences	Negative associations for rapport building and expression of preferences only Involvement in decision making not entered into analysis
28. Maly et al, (2008) (Maly, Stein, Umezawa, Leake, & Anglin, 2008)	USA	Breast cancer patients	Questionnaire	257	Education and income	Question asking, raising concerns, involvement in decision making, and expression of opinions, preferences and emotions	Positive associations
29. Manderbacka, (2005) (Manderbacka, 2005)	Finland	Coronary heart disease patients	Qualitative interviews	30	Occupation and employment	Involvement in decision making	No statistical analyses performed
30. Mercer et al, (2016) (Mercer et al., 2016)	UK (Scotland)	Patients attending a GP practice	Questionnaire	659	Scottish Indices of Multiple Deprivation	Involvement in decision making	Positive association
31. Moise et al, (2017) (Moise, Ye, Alcantara, Davidson, & Kronish, 2017)	USA	Patients with uncontrolled hypertension	Questionnaire	195	Education and insurance	Involvement in decision making	Positive association for education only
32. Moret et al, (2017) (Moret,	France	Gynaecology, orthopaedic,	Questionnaire	255	Deprivation (EPICES score	Involvement in decision making	Positive association

Anthoine, Pourreau, Beaudeau, & Leclere, 2017)		internal medicine, and emergency medicine hospital inpatients			and perceived social status), education, and employment		for deprivation only Other variables not entered into analysis
33. Morishige et al, (2017) (Morishige, Nakajima, Yoshizawa, Mahlich, & Sruamsiri, 2017)	Japan	Inflammatory bowel disease patients	Questionnaire	1035	Income, education and employment	Involvement in decision making	No associations
34. Morrison et al, (2003) (Morrison, Murphy, & Nalder, 2003)	Australia	General population	Questionnaire	1297	Education and income	Involvement in decision making, and expression of preferences	Negative associations
35. Murray et al, (2007) (Murray, Pollack, White, & Lo, 2007)	USA	General population	Questionnaire	3177	Education, income and insurance	Involvement in decision making	Positive associations for education and income only
36. Nijman et al, (2014) (Nijman, Hendriks, Brabers, de Jong, & Rademakers, 2014)	The Netherlands	General population	Questionnaire	1432	Education and income	Involvement in decision making	Positive associations
37. Olson et al, (2010) (Olson & Windish, 2010)	USA	Hospital inpatients	Questionnaire	89	Education and insurance	Involvement in decision making	No associations
38. Overgaard et al, (2012)	Denmark	Low risk women receiving	Questionnaire	375	Education and employment	Involvement in decision making	No associations

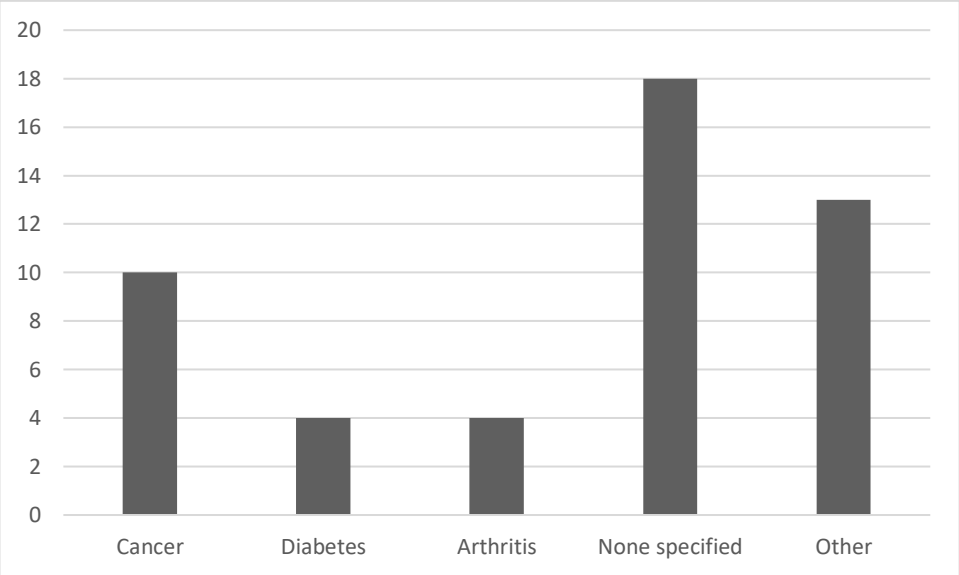
(Overgaard, Fenger-Gron, & Sandall, 2012)		midwifery unit or obstetric unit care					
39. Phipps et al, (2008) (Phipps, Madison, Polansky, & Tester, 2008)	USA	African American cancer patients who received chemotherapy	Questionnaire	26	Income and education	Involvement in decision making	No associations
40. Rademakers et al, (2012) (Rademakers et al., 2012)	The Netherlands	Patients with rheumatoid arthritis, spinal disc herniation, or malignant or benign breast abnormalities	Questionnaire	1019	Education	Involvement in decision making and question asking	Positive associations
41. Skolasky et al, (2011) (Skolasky et al., 2011)	USA	Community dwelling multimorbid adults	Questionnaire	855	Education and income	Involvement in decision making	Positive association for education only
42. Smith et al, (2016) (Smith, Pandit, Rush, Wolf, & Simon, 2016)	USA	General population	Questionnaire	3400	Income and education	Involvement in decision making	Positive associations
43. Spies et al, (2006) (Spies et al., 2006)	Germany	Patients attending a chronic pain clinic	Questionnaire	341	Income, employment and education	Involvement in decision making and question asking	Positive associations for education only
44. Stepleman et al, (2010) (Stepleman et al., 2010)	USA	Multiple sclerosis patients	Questionnaire	199	Education and employment	Involvement in decision making	Positive associations

45. Tariman et al, (2014) (Tariman, Doorenbos, Schepp, Singhal, & Berry, 2014)	USA	Symptomatic myeloma patients	Questionnaire	20	Employment, education, and income	Involvement in decision making	No associations
46. Tsimtsiou et al, (2014) (Tsimtsiou, Kirana, & Hatzichristou, 2014)	Greece	Hospitalised patients	Questionnaire	454	Education and income	Involvement in decision making and question asking	Positive associations for education only Income not entered into analysis
47. van den Brink-Muinen et al, (2011) (van den Brink-Muinen, Spreeuwenberg, & Rijken, 2011)	The Netherlands	Patients diagnosed with a somatic chronic disease	Questionnaire	2423	Education	Involvement in decision making	No association
48. Yek et al, (2017) (Yek et al., 2017)	Singapore	Patients attending a pre-operative evaluation clinic for elective surgical procedures	Questionnaire	364	Education, employment, insurance and income	Involvement in decision making and question asking	Positive associations for education, employment, and insurance only Income not entered into analysis
49. Yeo, (2016) (Yeo, 2016)	USA	General population	Questionnaire	2297	Education, employment, income and insurance	Involvement in decision making and question asking	Negative associations for education

							and income only Positive associations for insurance Employment not entered into analysis

Most of the studies used questionnaires to collect their data (75.5%, *n* = 42), while qualitative techniques such as interviews and focus groups were relatively rare (10.2%, *n* = 5). Only 2 of the studies were interventions, both of which were pilot studies with no control group. Cancer was the most commonly studied condition (20.4%, *n* = 10), with only one study recruiting head and neck cancer patients. Only 4 studies recruited arthritis patients and 4 recruited diabetes patients. However, most studies did not specify what condition (if any) their participants had (36.7%, *n* = 18). 'Other' conditions included asthma, chronic pain, HIV, multiple sclerosis, and inflammatory bowel disease (Fig. 5.4). None of the three UK studies recruited cancer patients.

Figure 5.4. Diagnoses of recruited participants



Secondary or tertiary care was the most common study setting (44.9%, *n* = 22), as only 11 studies were set in primary care, while 16 studies did not specify what setting their research referred to when collecting data from participants. Involvement in decision-making was the most commonly studied patient participation behaviour (93.9%, *n* = 46), while 5 studies looked at raising concerns and only one looked at rapport building. Question-asking and expression of opinions, preferences or

emotions was more commonly studied, featuring in 13 and 12 studies respectively. The rapport building study recruited participants from the general population and so there was a lack of studies which focused on rapport building which involved participants in a health setting. Three of the raising concerns studies were with breast cancer patients (Table 5.2).

Education level was the most commonly used measure of SES (91.8%, n = 45), while only 4 studies used occupation, and only 2 used a composite measure of deprivation. One study measured housing situation and receipt of benefits, one used a composite measure of social class, and one examined financial strain and finances at the end of the month. Also of note was that many studies looked at more than one type of patient participation behaviour or measure of SES. The majority of studies used more than one measure of SES (67.3%, n = 33), while 18 studies looked at more than one type of patient participation behaviour (Table 5.2).

Tables 5.1 and 5.3 show the direction of associations reported in the included studies. Of the 49 included studies, 5 did not perform statistical analyses as they had employed qualitative methodologies. Positive associations between SES and patient participation behaviours (PPB) were reported by 24 studies, while 5 studies reported negative associations. Twenty-seven studies reported no association between at least some of their variables. Eleven studies reported associations of differing directions for different measures of SES or different PPBs within their study. Since the studies were so mixed in terms of design, participants' condition, outcomes and setting, it was not appropriate to undertake any meta-analyses.

Of the 23 studies conducted in the USA, 13 reported a positive association between SES and PPB, 2 reported a negative association, and 14 reported no association

between at least some of their variables. Three studies did not perform statistical analyses, and 9 studies reported associations of differing directions for different measures of SES and PPB.

Of the 10 studies conducted with cancer patients, 4 reported a positive association between SES and PPB, 7 reported no association between at least some of their variables, and 2 reported associations of differing directions for different measures of SES and PPB. One study did not perform statistical analyses.

Table 5.2. Summary of SES variables and patient participation behaviours used in included studies

		Patient participation behaviours				
		Involvement in decision-making	**Question asking**	**Raising concerns**	**Rapport building**	**Expression of opinions, preferences or emotions**
SES measure	**Education**	1, 2, 3, 4, 5, 6, 8, 11, 12, 14, 15, 16, 17, 20, 21, 22, 23, 24, 25, 26, 27, 28, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49	1, 7, 18, 21, 23, 25, 28, 40, 43, 46, 48, 49	9, 18, 23, 25, 28	27	1, 2, 10, 11, 17, 18, 21, 22, 23, 27, 28, 34
	Employment	2, 3, 6, 17, 23, 29, 32, 33, 38, 43, 44, 45, 48, 49	23, 43, 48, 49	9, 23		2, 17, 23
	Income	3, 6, 22, 23, 24, 27, 28, 33, 34, 35, 36, 39, 41, 42, 43, 45, 46, 48, 49	23, 28, 43, 46, 48, 49	9, 23, 28	27	22, 23, 27, 28, 34
	Occupation	12, 13, 29	13			10
	Insurance	8, 31, 35, 37, 48, 49	7, 48, 49	9		
	Deprivation	30, 32				
	Receipt of benefits	3				
	Housing situation	3				
	Social class	19				

Financial strain	20
Finances at end of month	20

Each study in Table 1 was assigned a number, which corresponds with the numbers in this table

Table 5.3. Box score review of reported statistical associations

Patient participation behaviour	**Number of studies**	
Question asking	13	0000+++++++++
Raising concerns	5	000++
Involvement in decision-making	45	000000000000000000000++++++++++++++++++++
Rapport building	1	+
Expression of opinions, preferences and emotions	12	00000000++++
SES measure		
Education	45	000000000000000000000++++++++++++++++++++
Employment	15	0000000000000++
Income	20	0000000000000+++++++
Occupation	4	0000
Insurance	8	00000+++
Deprivation	2	++
Receipt of benefits	1	0
Housing situation	1	0
Social class	1	+

5.4 Discussion

5.4.1 Summary of findings

The aim of this review was to map the literature on why tendency to and desire for patient participation behaviours in doctor-patient interactions differs by SES, and to look at what aspects of SES have been explored in such studies.

I found that the most commonly used measure of SES was education and the most commonly studied patient participation behaviour was involvement in decision-making. Most of the studies had been conducted in the USA, making the literature very US-centric.

5.4.2 Comparison with previous literature

My review found significantly more studies (49) than Verlinde et al., (2012) who included only 20 studies, despite the fact that I focused exclusively on patient participation behaviours and not doctor behaviours while they used a relatively broad search strategy. Given that 24 of the papers I included were published after 2012, this may be partly due to more studies in the field being published after their review, however that still leaves 5 papers which should theoretically have been picked up by their review. It may also be indicative of an expanding area of research or due to my use of a wider set of SES indicators. Interestingly, only one of the studies I included was also included in the Verlinde et al., (2012) review (Murray et al., 2007). Eleven of the papers included in their review looked at patient participation behaviours, of which, one was conducted before 1980 (1972), one looked at paediatric consultations, and 8 did not actually elicit patient perspectives of participation behaviours (either because they only analysed consultation recordings or the 'patient variable' studied was not a participation behaviour). This left only the Murray et al. (2007) study.

I found that the most commonly studied measure of SES in this field was education level, while occupation, and to a lesser extent income and employment status, were relatively neglected in the literature. Occupation is a key indicator of SES and likely to have an important influence on the doctor-patient relationship (Galobardes et al., 2006a), and so it is surprising to find so few previous studies using this measure.

I found that involvement in decision-making was the most commonly studied patient participation behaviour, with raising concerns and building rapport being relatively neglected by the literature. Given that previous research has found positive outcomes associated with rapport building (Arora, 2003; R. M. Epstein, Fiscella, Lesser, & Stange, 2010; Hall et al., 1988), it is important that further research is carried out in this area.

Although the most common condition studied was cancer and the most common setting was secondary or tertiary care, a large proportion of studies did not specify what condition their participants had been diagnosed with or the setting which their study referred to. This is potentially important information which is missing from these studies, as setting and condition which the patient is consulting for can influence a patient's preferred and experienced level of participation in a consultation (Deber, Kraetschmer, Urowitz, & Sharpe, 2007; Degner & Sloan, 1992; Ronald M Epstein & Street JR, 2007).

I found that of the three studies conducted in the UK, none recruited cancer patients. Furthermore, of the 10 studies recruiting cancer patients only one study involved head and neck cancer patients. This suggests that there is a lack of research on socioeconomic differences in patient participation behaviours for head and neck

cancer patients in the UK. My study which is described in Chapter 8, addresses this gap in the literature.

Most studies included in the review were conducted in the USA, making the current research in this area very US-centric. In the USA there is a greater use of private healthcare in comparison to in the UK, which has been linked to significant inequalities in health (Kim & Richardson, 2012). This may limit the generalisability of the results of these studies, as other countries have differently structured healthcare systems which might influence patient participation behaviours. There is a need for more patient participation studies outside of the USA.

5.4.3 Implications

Most studies used more than one measure of SES which in some cases allowed a comparison of the effects of each different measure, although in some of these, not all the SES variables were entered into the analysis but were simply used to describe the sample. The objective of my study was to map the literature in this area rather than to produce a synthesis across several types of studies, however I extracted data from included studies on whether a statistically significant association between SES and PPB had been reported. This indicated that although PPB were found to be related to SES in about half of the studies, in about half, they were not. Summarising results is made more difficult by the heterogeneity which exists between studies in this area, and the range of different measures of SES and indicators of PPB which had been used. For example, although several studies showed an association with education and patient participation behaviours, as many as 17 studies found no statistically significant association between the two variables; and so the relationship is likely to be complex. On the other hand, few studies seem to have found a significant association between patient participation behaviours and employment or

income. Larger and more sophisticated studies are needed, using a range of SES indicators and a more in-depth description of patient participation behaviours, and the setting involved.

5.4.4 Limitations

However, the limitations to my review are that I did not do any hand searching of journals, backwards and forwards citation chasing, or contacting experts in the field. This is because the initial scoping search showed this to be a very wide field, and so these would not have been manageable within the time and resources available. Therefore this is not an exhaustive review, but simply provides an overview of the patterns of literature on SES and patient behaviours.

5.5 Conclusion

In conclusion, my study suggests that education is the most commonly used measure of SES, and involvement in decision-making is the most commonly researched patient participation behaviour in this field. The majority of studies are conducted in the USA, and many do not specify important information such as patient condition and setting. There is a lack of UK-based research on patient participation behaviours with head and neck cancer patients.

Therefore my studies described in Chapters 7 and 8 address these gaps by examining raising concerns, rapport building, and a wider range of SES measures within a UK-based context with head and neck cancer patients.

Chapter 6: Is social inequality related to different patient concerns in routine oral cancer follow-up clinics?

6.1 Introduction

As outlined in Chapter 3, individuals of low socioeconomic status (SES) are more likely to develop head and neck cancer than high SES individuals (Auluck et al., 2014; Colevas, 2014; Conway et al., 2010; Hwang et al., 2013; Thorne et al., 1997), which seems to be mainly mediated by alcohol consumption and smoking rates (Conway et al., 2010). Recent studies have also found that low SES head and neck cancer patients experience poorer quality of life as measured by the University of Washington Quality of Life questionnaire (UW-QoL; designed specifically for use in head and neck cancer), particularly in the socio-emotional subscale, and worse survival rates as measured by the Office of National Statistics and tracked between 2008 and 2014 following treatment for oral cancer (Ghazali et al., 2013; Rylands et al., 2016a, 2016b; Woolley et al., 2006).

According to the World Health Organisation (WHO), quality of life is the perception an individual has of their place in life in relation to their expectations, goals, culture and values. In other words, this is framed by an individual's expectations in comparison with their reality. Quality of life is affected by a wide range of factors including physical functioning, mental health, autonomy, physical symptoms, and relationships (Herrman et al., 1993). Health related quality of life (HRQoL) is a similar concept which focuses specifically on health problems and how they might impact the various aspects of quality of life, such as relationships, work, independence and emotional wellbeing. HRQoL does not measure aspects of quality of life such as economic status or environment (McGee & Ring, 2010). HRQoL can

be measured using five different types of instruments: generic, disease or population specific, dimension specific, individualised and utility (McGee & Ring, 2010).

Generic instruments assess a range of quality of life dimensions but do not produce a total score of all subscales (McGee & Ring, 2010): examples include the Functional Limitations Profile and the Medical Outcomes Study Short-Form 36 (Coons, Rao, Keininger, & Hays, 2000; Garratt, Schmidt, Mackintosh, & Fitzpatrick, 2002). Dimension specific measures assess a specific aspect of quality of life (McGee & Ring, 2010), such as the Hospital Anxiety and Depression scale (Herrmann, 1997) and the Global Mood Scale (Denollet & Brutsaert, 1995). Utility measures assess how an intervention might affect both quality of life and length of life by calculating quality-adjusted life years, such as the EuroQol (McGee & Ring, 2010). Disease or population specific measures assess factors which are relevant to particular health problems or populations (McGee & Ring, 2010), and include instruments such as the Arthritis Impact Measurement Scales (Meenan, Mason, Anderson, Guccione, & Kazis, 1992), Parkinson's Disease Questionnaire (Peto, Jenkinson, Fitzpatrick, & Greenhall, 1995) and the University of Washington Quality of Life questionnaire (UW-QoL) which has been developed for use with head and neck cancer patients (Kanatas et al., 2012). Individualised measures allow the individual to select the aspects of quality of life which are most important to them, and can be generic or disease specific (McGee & Ring, 2010); the UW-QoL is an example of a measure which is disease specific and has elements which are individualised (Kanatas et al., 2012). Therefore HRQoL is an important concept which is subjectively determined by the patient, but can be measured in a number of ways.

In Chapter 4 I outlined the literature which suggests that low SES patients participate less actively in their care by behaviours such as asking fewer questions and

volunteering less information unprompted during a medical consultation (section 4.4.1.4). However doctors involve low SES patients less in their appointments by behaviours such as asking low SES patients fewer questions and making less attempts at building a rapport (section 4.3.6.4). These patients therefore access fewer appropriate services than high SES patients, which may be due in part to low self-esteem, as an earlier study comparing oral cancer patients with non-cancer patients found lower reported levels of self-esteem in oral cancer patients (S. N. Rogers, McNally, Mahmoud, Chan, & Humphris, 1999).

Poor doctor-patient communication may lead to poor health outcomes. A consultation lacking in understanding and acceptance of the patient's issues or with poorly executed attempts at empathy and reassurance can cause the patient to feel dismissed and therefore potentially reduce treatment adherence and increase reluctance to consult with a healthcare professional in the future (Greville-Harris & Dieppe, 2015). If patients from low socioeconomic backgrounds are receiving poorer quality communication during appointments, perhaps this would partly explain the higher rates of morbidity and mortality and lower HRQoL present in head and neck cancer. Poor communication during appointments can also result in low adherence to treatment and advice due to the patient's confusion about their treatment (Jones, Smith, & Llewellyn, 2015); this may be another reason why health outcomes and Quality of Life are worse in low SES patients (Ghazali et al., 2013; Woolley et al., 2006). Therefore the worse health-related quality of life (HRQoL) in low SES patients may be due in part to their issues with expressing needs to a healthcare professional. Follow-up appointments at the head and neck cancer clinic allow the consultant to perform a check-up on the patient to determine if their cancer may have returned, but it is also an opportunity for the patient to raise any concerns

which they may have. These concerns, whether physical, emotional, or psychological, can then be addressed by the consultant themselves, or referred to another healthcare professional.

As described in Chapter 4 (section 4.9.3.1), The Patient Concerns Inventory (PCI) was designed to facilitate discussion between patients and professionals during appointments to ensure that needs are met which the patient might find difficult to bring up during clinical encounters (S. N. Rogers & Lowe, 2014). The PCI-HN is a 56-item question prompt list of concerns specific to head and neck cancer patients, ranging from physical, treatment-related, social-care, and psychological, as well as a section to indicate any specific professionals or support staff the patient may wish to speak to (S. N. Rogers & Lowe, 2014). This is given to patients while they are waiting for their head and neck oncology review appointment with the consultant. This is completed in a separate room off of the waiting area, where a volunteer is on hand to assist the patient in completing the forms, and the completed forms are then sent to the consultant for use in the patient's appointment.

In theory the PCI may help to resolve the issue of worse HRQoL outcomes in low SES patients through improved doctor-patient communication, helping patients to raise concerns with their consultant, however its efficacy in improving doctor-patient communication has not yet been studied. As mentioned in the previous chapter, various studies have been conducted on patients' use of the PCI, however this was the first study which examined differences in PCI responses by patient SES.

Therefore the research question for this study was: do PCI responses differ across the socioeconomic gradient in patients attending routine oral cancer follow-up clinics, and how do they differ?

Based on the literature summarised above, one might expect patients at the lower end of the socioeconomic gradient to select fewer items on the PCI than higher SES patients.

6.2 Methods

At the start of my PhD I wrote the introduction and discussion for a paper reporting the results of a retrospective study on the use of the Patient Concerns Inventory (PCI) in head and neck cancer follow-up clinics. I worked with a research group to help interpret and report this data in the early stages of my research in the area of SES differences in doctor-patient communication. Our aim was to determine whether use of the PCI differed, based on patient's area-level deprivation, as measured by Indices of Multiple Deprivation (IMD).

This provided a useful context for my PhD when planning what work I would undertake as part of my studies, and partly informed the design of my study which is described in Chapter 8.

Ethical approval for this study was obtained from the Clinical Audit Department at Aintree University Hospital. As anonymous data, this study was under clinical audit/ service evaluation approval - CAMS 2231 (Appendix 7). The Aintree University Hospital records were used to retrospectively find eligible patients treated for primary head and neck squamous cell oral cancer between 2008 and 2012 from one Maxillofacial Unit (MFU) consultant's clinic. Patients were excluded if they lived overseas or had been diagnosed with cutaneous or salivary gland malignancy. There was no formal sample size calculation. There were two constraints on the patient cohort –one being when the PCI was introduced and the second being the availability

at the time the study ran of comprehensive clinical data in the data set – in effect to the end of 2012. Thus the 2008-2012 cohort was selected by default.

Patients were asked to fill out the PCI and UW-QoL questionnaire while in the waiting room, before their MFU consultation as part of their routine care. Using the PCI was not mandatory, and some patients declined to use it. If they agreed, they were taken into a small room off of the waiting area to complete these forms using an iPad. A volunteer was on hand to help patients use the technology or read the questions if they had limited literacy skills. This allowed researchers to engage typically hard-to-reach patients who have either limited literacy skills or experience using computers. This was participants' first use of the PCI in clinic, and it occurred between 1.7 to 9.6 months post-surgery (or post-diagnosis if they did not receive surgery). While there was no data collected on how long it took patients to complete the PCI, a previous study found that the median time it took patients to complete the PCI on a touch screen was 8 minutes (S. N. Rogers et al., 2009).

Patient postcodes at diagnosis were also used to obtain the patient's IMD 2010 quartile if they were residing in England (some patients seen at Aintree Hospital live in the Isle of Man or Wales, which do not have any IMD data available). As was described in Chapter 3, IMD is an area-level based measure of SES which uses census data to classify small areas in terms of the deprivation present in the environment. It is not an individual measure of SES, but it is comparatively easy to obtain the data. Typically IMD scores are split into quintiles or deciles, however for the present study quartiles were used. This is because the sample size was not particularly large, therefore the researchers felt it would be best to use quartiles. The consultant obtained postcodes from clinical records for patients attending their clinic,

and these postcodes were then turned into IMD quartiles and analysed by a medical statistician.

Kaplan-Meier methods were used to estimate cumulative survival with survival curves compared using the log-rank test. Fisher's exact test and Chi-squared test were used to compare patient an clinical characteristics by whether or not they used the PCI, and by IMD quartile (comparing the most deprived quartile with the other three quartiles). The Mann-Whitney test was used to compare patient age by PCI use, and compare number of PCI items (overall and for domains) selected by IMD quartile. Spearman correlation was used to look at the association between overall IMD score and total number of PCI items selected.

6.3 Results

The records of 131 patients were screened to check for eligibility. Of these, 106 were eligible for the study, and of the 25 excluded, 15 were palliation cases, 7 were followed up at another facility, 2 had cognitive impairment, and 1 was an ambulance patient. Of the eligible patients, 90 participated in the study. Of those 90, 87 patients had IMD data available for their place of residence at diagnosis. Those who participated in the study were younger (less than 75 years of age) and less likely to have advanced stage cancer than those who did not participate. This difference was significant (Table 6.1). Furthermore, using Kaplan-Meier methods those who participated had an estimated survival of 92% at 12 months and 84% at 24 months versus 50% at 12 months and 44% at 24 months for those who did not use the PCI ($p = .001$). The median (IQR) time from surgery (or from diagnosis if no surgery) to first clinic was 4.0 (1.7–9.6) months.

Table 6.1: Patient and clinical characteristics of the cohort of 106 Oral cancer patients for whom the PCI could have been used

		% using PCI	P value
All patients		85% (90/106)	
Gender	Male	85% (50/59)	>0.99*
	Female	85% (40/47)	
Age	Median (IQR))	PCI: 63 (56-73) n=90 No PCI: 78 (69-84), n=16	<0.001***
	<55	95% (18/19)	
	55-64	97% (34/35)	
	65-74	80% (20/25)	
	75-84	71% (15/21)	
	85+	50% (3/6)	
IMD quartile based on national ranks	Q1 Most deprived	89% (47/53)	
	Q2	87% (13/15)	
	Q3	80% (16/20)	0.69**
	Q4 Least deprived	79% (11/14)	
	Q1 Most deprived	89% (47/53)	0.41*
	Q2-Q4	82% (40/49)	
	IMD not known	75% (3/4)	
Tumour site	Buccal	82% (14/17)	
	Lower gum	85% (11/13)	
	Tongue (ant 2/3)	83% (40/48)	0.89**
	FOM	87% (20/23)	
	Other	100% (5/5)	
Overall TN stage	1-2	90% (64/71)	0.08* excluding Not known
	3-4	76% (26/34)	
	Not known	- (0/1)	
Primary Treatment	Surgery only	86% (54/63)	
	Surgery + RT/CRT	84% (32/38)	0.93**
	RT/CRT not surgery	80% (4/5)	
Year of operation or diagnosis if no surgery	2008	87% (26/30)	
	2009	83% (19/23)	
	2010	85% (22/26)	0.42**
	2011	73% (11/15)	
	2012	100% (12/12)	

*Fishers exact test

** Chi-squared test,

***Mann-Whitney test comparing age distributions between the 2 IMD groups

The majority of participants (54%) were living in the most deprived quartile at diagnosis, with 15% in IMD quartile 2, 18% in quartile 3, and 13% in the least deprived quartile. When looking at the gender of participants 68% of men lived in the most deprived quartile, compared to only 35% of women ($p = .004$). Patients in the most deprived quartile were 4 years younger on average ($p = .14$) with 63% of those aged under 65 years and 42% of those aged 65 years and over living in the most deprived quartile (Table 6.2).

Table 6.2: Patient and clinical characteristics and IMD 2010 status of the cohort of 87 Oral cancer patients who used the PCI and for whom there were IMD deprivation data

		% Living in IMD Q1 most deprived quartile based on National ranks	P value
All patients		54% (47/87)	
Gender	Male	68% (34/50)	0.004*
	Female	35% (13/37)	
Age	Median (IQR))	IMD Q1: 62 (55-69) n=47 IMD Q2-Q4: 66 (58-75), n=40	0.14***
	<55	65% (11/17)	
	55-64	62% (21/34)	
	65-74	39% (7/18)	
	75+	44% (8/18)	
Tumour site	Buccal	62% (8/13)	
	Lower gum	55% (6/11)	
	Tongue (ant 2/3)	45% (17/38)	0.40**
	FOM	70% (14/20)	
	Other	40% (2/5)	
Overall TN stage	1-2	49% (30/61)	0.24* excluding Not known
	3-4	65% (17/26)	
Primary Treatment	Surgery only	55% (28/51)	
	Surgery + RT/CRT	53% (17/32)	0.97**
	RT/CRT not surgery	50% (2/4)	
Year of operation or diagnosis if no surgery	2008	60% (15/25)	
	2009	53% (9/17)	
	2010	45% (10/22)	0.83**
	2011	64% (7/11)	
	2012	50% (6/12)	

*Fishers exact test

** Chi-squared test,

***Mann-Whitney test comparing age distributions between the 2 IMD groups

Some of the most commonly raised concerns were fear of recurrence, chewing/eating, dental health/teeth, dry mouth, and pain in the head and neck (Tables 6.3 and 6.4).

There was no significant difference in the number of PCI items selected by patients in different IMD quartiles (Table 6.3), with a Spearman correlation coefficient of r = -.01, p = .93. There was also no significant difference by IMD in terms of the type of concerns selected (Table 6.4). Patients from the most deprived quartile used the PCI less often (median 3 times) than patients from the other 3 quartiles (median 4 times), however this difference was not significant (p = .21 Mann–Whitney test). Patients in the most deprived quartile and those in the other 3 quartiles both had a 24-month survival of 83% (SE 6%), p = .28 log-rank test for comparison of survival curves.

Table 6.3: The number of PCI items selected overall, and for each PCI domain, by IMD 2010 deprivation group

	Most deprived national IMD quartile Q1 (N=47) Median (IQR) IMD score: 54 (43-64)	Less deprived national IMD quartiles Q2-Q4 (N=40) Median (IQR) IMD score: 14 (9-19)	P value*
(A) Physical and Functional well-being (29 items):			
• **No items selected**	19% (9)	8% (3)	
• **One**	21% (10)	20% (8)	
• **Two**	13% (6)	20% (8)	
• **Three-Four**	15% (7)	23% (9)	
• **Five-Nine**	28%(13)	28% (11)	
• **Ten-Twelve**	4% (2)	3% (1)	
Median (IQR), Mean	2 (1-6), 3.51	3 (1-5), 3.50	0.61
B) Psychological and Emotional well-being/Spiritual (14 items):			
• **No items selected**	36% (17)	38% (15)	
• **One**	40% (19)	33% (13)	
• **Two**	6% (3)	20% (8)	
• **Three-Six**	17% (8)	10% (4)	
Median (IQR), Mean	1 (0-1), 1.17	1 (0-2), 1.02	0.97
(C) Social care/Social well-being (9 items):			
• **No items selected**	66% (31)	68% (27)	
• **One**	26% (12)	30% (12)	
• **Two-Three**	9% (4)	3% (1)	
Median (IQR), Mean	0 (0-1), 0.47	0 (0-1), 0.35	0.73
(D) Treatment-related (4 items):			
• **No items selected**	87% (41)	73% (29)	
• **One**	9% (4)	23% (9)	
• **Two**	4% (2)	5% (2)	
Median (IQR), Mean	0 (0-0), 0.17	0 (0-1), 0.33	0.10
Total number of PCI items (56 items)			
• **No items selected**	9% (4)	8% (3)	
• **One**	13% (6)	-	

• **Two**	21% (10)	13% (5)	
• **Three-Four**	9% (4)	30% (12)	
• **Five-Nine**	32% (15)	35% (14)	
• **Ten-Nineteen**	17% (8)	15% (6)	
Median (IQR), Mean	4 (2-8), 5.32	4 (3-8), 5.20	0.46
Total number of health professionals:			
• **No items selected**	51% (24)	50% (20)	
• **One**	30% (14)	33% (13)	
• **Two**	11% (5)	10% (4)	
• **Three-Five**	9% (4)	8% (3)	
Median (IQR), Mean	0 (0-1), 0.81	0 (0-1), 0.78	>0.99

*Mann-Whitney test comparing N of PCI item distributions between the 2 IMD groups

Table 6.4: Concerns raised by 20% or more of patients on the PCI, by IMD 2010 deprivation group

IMD Q1 (n=47)		**IMD Q2-Q4 (n=40)**	
Concern	**%**	**Concern**	**%**
Fear of the cancer coming back	43	Chewing / Eating	45
Sore Mouth*	43	Fear of the cancer coming back	43
Dry mouth*	29	Dental health / teeth	38
Dental health / teeth	28	Mouth opening	23
Chewing / Eating	26	Pain in head and neck	23
Fatigue / tiredness	26	Dry mouth**	22
Pain in head and neck	21	Pain elsewhere	20
Sleeping	21	Swallowing	20
Speech	21		
Swallowing	21		

Some items were added later to the PCI:

*based on n=14

**based on n=9

However significantly more patients from the most deprived IMD quartile reported problems with mood ($p = .004$) and recreation ($p = .02$) using the UW-QoL questionnaire, compared to patients in the other three quartiles. More patients in the most deprived quartile also reported their quality of life was less than good (36%) compared to patients in less deprived quartiles (18%), however this was not significant ($p = .09$, Table 6.5). These UW-QoL findings were still reported even when the data was stratified by treatment and by overall clinical TNM stages (1–2 and 3–4). There were no other differences by IMD quartile.

Table 6.5: Association of IMD 2010 deprivation group with UW-QOL dysfunction, UW-QOL subscale scores and UW-QOL overall quality of life scale

	Most deprived national IMD quartile Q1 (N=47)	Less deprived national IMD quartiles Q2-Q4 (N=40)	P value*
UW-QOL physical function subscale :			
% with Dysfunction:			
• **Appearance**	11% (5/47)	15% (6/39)	0.54
• **Swallowing**	28% (13/47)	13% (5/39)	0.12
• **Chewing**	11% (5/47)	10% (4/39)	>0.99
• **Speech**	11% (5/47)	3% (1/39)	0.22
• **Taste**	9% (4/47)	8% (3/39)	>0.99
• **Saliva**	16% (7/45)	16% (6/38)	>0.99
Physical function subscale score (0-100): Median (IQR)	72 (58-86), n=47	73 (60-88), n=40	0.51
UW-QOL social-emotional function subscale			
% with Dysfunction :			
• **Pain**	23% (11/47)	28% (11/39)	0.63
• **Activity**	11% (5/47)	18% (7/39)	0.37
• **Recreation**	26% (12/47)	5% (2/39)	0.02
• **Shoulder**	15% (7/47)	8% (3/39)	0.34
• **Mood**	30% (14/47)	5% (2/39)	0.004
• **Anxiety**	15% (7/47)	10% (4/39)	0.75
Social-emotional function subscale score (0-100): Median (IQR)	73 (53-88), n=47	76 (62-87), n=40	0.18
% with less than good overall QOL	35% (16/46)	18% (7/39)	0.09

* Fishers Exact test, apart from Mann-Whitney test to compare subscale scores

6.4 Discussion

This is the first study to examine whether there is an association between IMD quartile and raising concerns in head and neck cancer consultations in the UK. The fact that 85% of eligible patients used the PCI prior to their consultation suggests that the PCI is feasible for patients to use within a busy clinic environment. Therefore it could potentially be implemented into other clinics.

More than half (54%) of the patients who participated were living in the most deprived quartile. This is in line with various studies which have found that individuals from low SES backgrounds were more likely to develop head and neck cancer (Auluck et al., 2014; Colevas, 2014; Conway et al., 2010; Hwang et al., 2013; Thorne et al., 1997). For example, Conway et al., (2010) found that 34 % of head and neck cancer patients in their sample were in the most deprived SIMD quintile (Conway et al., 2010). Auluck et al., (2014) found that for oropharyngeal cancer 29.8% of men and 28.1% of women were in the most deprived quintile, and for oral cavity cancer 33.6% of men and 25.7% of women were in the most deprived quintile of an area-based measure developed for use in Canada (Auluck et al., 2014). Purkayastha et al., (2016) found that 15.1% of head and neck cancer patients in their sample were living in the most deprived Carstairs decile (Purkayastha, McMahon, Gibson, & Conway, 2016).

The percentage of patients in the most deprived areas seems to be higher in the present study than in those just mentioned, which could be due to a number of reasons. Firstly different measures of area-level deprivation were used in each study, therefore their criteria for the most deprived areas may differ slightly. Secondly, the present study divided patients into quartiles whereas the other studies used quintiles or deciles, which makes comparison difficult. If the present study also used quintiles

or deciles then the percentage of deprived patients may have been much more similar to the other studies. It is possible that by grouping IMD scores by quartiles rather than quintiles or deciles, some of the value as a discriminatory measure of SES differences may have been lost, because such a large proportion were in the lowest quartile. However as this was a retrospective study, the small sample size which necessitated the use of quartiles was unavoidable. Finally, the other studies were conducted in Scotland and Canada. It is possible that the areas served by the clinic in the present study may have been more deprived than the areas which the other studies recruited from.

Contrary to the hypothesis, there were no significant differences by patient IMD in terms of the number of concerns raised using the PCI. Based on the literature summarised in Chapter 4, we might have expected patients in the more deprived quartiles to raise fewer concerns than those in less deprived quartiles, however that does not seem to be the case. It may be that low SES patients selected concerns on the PCI, but there were then differences in how they discussed these with the consultant compared with higher SES patients. Or perhaps high SES patients raised additional concerns in the consultation, without reporting them on the PCI. Given that this was the participants' first time using the PCI, potentially they all approached using it in a similar manner, however perhaps after using it in multiple visits over a prolonged period of time we might start to see some SES differences in the selection of items. Also the number of clinic visits which the patient had prior to participating in the study had not been recorded. This could be a useful variable for future studies as it may impact the relationship which the patient has with their consultant. Currently there is a study being conducted on use of the PCI over the

course of one year, so perhaps that will shed some light on the impact of long-term use (S. Rogers et al., 2019).

A post-hoc power calculation was carried out using G Power after the study had ended. It determined that in order to detect a medium effect size (0.3) the study had sufficient power (94%), however it did not have sufficient power to detect a small effect size (0.1, 27% power). This may potentially explain the lack of significant findings. If the effect size is small then it may have been detected with a larger sample.

Furthermore, patients in the most deprived quartile reported significantly more problems with mood and recreation than those in the less deprived quartiles. This suggests that patients from deprived areas experience worse quality of life, which is in line with the results of studies conducted by Rylands et al (2016a, 2016b). These studies also found that patients living in more deprived IMD quartiles reported worse quality of life, also using the UW-QoL, particularly with regard to socio-emotional issues, than their less deprived counterparts (Rylands et al., 2016a, 2016b). Previous studies have found that low mood is associated with stressful life events (Atkinson, Slater, Grant, Patterson, & Garfin, 1988), which suggests that the patients living in deprived areas in my study may experience more stressful life events, or perhaps they are less able to cope with such events due to a lack of resources. This is significant because low mood has been linked with a number of negative health outcomes, including reduced foetal growth in pregnant women as well as affecting the cardiovascular and immune systems (Hoffman & Hatch, 2000; Penninx et al., 2003; Trueba, Smith, Auchus, & Ritz, 2013).

These findings suggest that perhaps although low SES patients may be experiencing worse quality of life, they are not reporting these concerns to healthcare professionals. But it is possible that patients may have raised concerns during their consultation, despite not having selected them on the PCI. Therefore we need to find out more about what is happening in the consultation itself, by recording and observing consultations. My studies which are outlined in Chapters 8 and 9 address this.

There are a number of limitations to this study. Only oral cancer patients were recruited for this study, therefore the results may not be generalizable to other types of head and neck cancer. Furthermore, as the study only recruited patients from the Merseyside region the results may not be generalizable to other areas of the UK. The consultant's communication style may potentially have affected patients' reporting of concerns through the PCI. Given that communication styles between doctors can vary considerably, as mentioned in Chapter 4 (Cooper-Patrick et al., 1999; Debra L. Roter & Hall, 2004; Debra L. Roter et al., 2002), the fact that only one consultant was used in this study is another limitation. If a different consultant had taken part, then the results of the study may have been quite different. Furthermore, given that previous research has found that a doctor's gender can influence their communication style (see section 4.3.5.1), the fact that the consultant in this study was male may have affected the results.

It is also possible that IMD was not a good measure of SES differences for this study, as it is not an individual measure of SES. If an individual measure such as education or occupation had been used, then perhaps a significant effect might have been found.

6.5 Conclusion

In conclusion, this study found that although patients from the most deprived quartile reported worse quality of life, they did not select significantly more items on the PCI than other patients. This suggests that low SES patients may not be raising concerns about their quality of life issues to healthcare professionals. However this study did not provide any data about what was actually happening in the consultation itself. I addressed this gap in my study which is presented in Chapter 7, where I analysed audio recordings of the consultation itself to look for differences by IMD in concerns raised.

Chapter 7: High levels of socioeconomic deprivation do not inhibit patients' communication of concerns in head and neck cancer review clinics

7.1 Introduction

The study outlined in Chapter 5 found that there were no significant differences by patient area-level deprivation in terms of the number of concerns raised using the Patient Concerns Inventory (PCI) (see section 4.9.3.1). Since this was an analysis of PCI responses it is possible that the patients raised concerns during the consultation without recording them on the PCI. Therefore it was identified that there was a need to find out more about the consultations themselves to examine if there were any SES differences in doctor-patient communication. Furthermore, the mapping review outlined in Chapter 5 identified the need for UK-based studies on raising concerns with head and neck cancer patients.

Follow-up consultations at the head and neck cancer clinic are important opportunities for patients to raise any concerns which they have with their consultant. These can then be addressed by the consultant or other healthcare professionals, making raising concerns a key patient participation behaviour to focus on. However there is a lack of research in this area. Therefore the aim of this study was to investigate the impact of area-level deprivation on patients' raising of concerns in head and neck cancer review clinic appointments. I hypothesised that patients from more deprived areas would raise fewer concerns.

In order to analyse the data for this study, I spent two weeks visiting St Andrews University to use their Observer software and also receive further training on the use of the Verona Coding Definitions of Emotional Sequences (VRCoDES).

Research question: Does the number of concerns raised during head and neck cancer consultations significantly differ depending on the patient's Indices of Multiple Deprivation (IMD) status?

Aim:

- To examine whether the number and type of concerns raised during head and neck cancer consultations significantly differ by the patient's IMD status.

7.2 Methods

As part of another study conducted by researchers at St Andrews University in a Head and Neck review clinic at Aintree Hospital 121 audiotapes of consultations at this clinic were collected. Only 43 of these tapes were previously analysed and published in a peer-reviewed journal (Zhou, Humphris, et al., 2015). These consultations were all with one maxillofacial unit consultant, and 11 tapes could not be matched to demographic data. Therefore 110 audiotapes were analysed using VRCoDES and compared by patient area-level deprivation.

As outlined in section 4.8.2.2, the Verona Coding Definitions of Emotional Sequences (VRCoDES) is a method of quantifying doctor-patient communication through patient's expression of cues and concerns, and healthcare professionals' responses to these expressions in medical consultations (Piccolo et al., 2017). A cue is a verbal or nonverbal hint that suggests an unpleasant emotion, whereas a concern is a clear expression of emotion which is explicitly verbalised.

Cues can be further divided into 7 categories: cue a is when vague or unspecified words or phrases are used to describe their emotions; cue b is verbal hints to hidden concerns, for example through use of profanities, metaphors, or unusual words; cue c is words or phrases which emphasise physiological or cognitive correlates of

unpleasant emotional states, for example sleep, concentration, appetite, or energy; cue d is neutral expressions which refer to issues of potential emotional importance that stand out from the narrative and refer to stressful life events; cue e is repetition of a previous neutral expression; cue f is a nonverbal cue, for example crying, sighing, or frowning; and cue g is a clear expression of an unpleasant emotion which happened in the past.

Area-level deprivation was measured using Indices of Multiple Deprivation (IMD) (*The English Indices of Deprivation 2015*, 2015) scores which were then divided into deciles, with 1 being the most deprived and 10 being the least deprived areas. IMD as an area-level measure of SES is outlined in Chapter 3.

The data was analysed using Pearson's correlation to examine associations with IMD decile, and Pearson's partial correlation was used to control for length of consultation.

Attempts were made to obtain data on what age participants left formal education, as an additional measure of SES, however that data was only available for a small number of participants (27 out of 110). Of these 27 patients most left school before the age of 16 (48.1%) with only 2 patients leaving formal education between 21 and 22 years old (7.4%). 18.5% left at the age of 16, 22.2% between 16 and 17, and only one patient left between 17 and 18 (3.7%).

Patient Concerns Inventory (PCI) data was also collected for 98 of these consultations, in addition to University of Washington Quality of Life (UW-QoL) scores (see Chapter 4). This was to collect data on patient's concerns and quality of life, however no significant associations were found with SES.

7.3 Results

The majority of the sample was male (63.6%), with an average age of 62.9 years (SD = 12.69). There was a range of 29 – 93 years. The mean consultation length was 9 minutes 17 seconds, with a range of 3 minutes 52 seconds to 21 minutes 55 seconds. Table 7.1 shows the distribution of IMD deciles in the sample.

Table 7.1. Distribution of IMD decile in sample

IMD decile	Percent of sample
1	30.9
2	9.1
3	4.5
4	1.8
5	10
6	9.1
7	10
8	10
9	8.2
10	6.4

Most of the sample were treated with surgery and radiotherapy (52.7%), were diagnosed with early stage cancer (50%), and whose primary cancer site was oral (51.8%). The mean time since diagnosis was 56.85 months (SD=51.74), with a range of 6 – 240 months (Table 7.2).

Table 7.2. Clinical characteristics of sample

Treatment		**Percent of sample**	
Surgery only		40.9	
Surgery with radiotherapy		52.7	
Radio/chemoradiotherapy without surgery		6.4	
Stage at diagnosis		**Percent of sample**	
Early		50	
Late		31.8	
Missing		18.2	
Primary cancer site		**Percent of sample**	
Oral		51.8	
Pharyngeal		25.5	
Other		22.7	
	Mean	**Standard deviation**	**Range**
Time since diagnosis (months)	56.85	51.74	6 - 240

The mean total number of cues and concerns per consultation is 1.81 (SD=2.4), with a range of 0 – 13. There were an average of 0.73 concerns per consultation (SD=1.2), with a range of 0 – 8, and the most commonly expressed cue was cue b (0.65, SD=1.08), with a range of 0 – 5. No instance of cue e or f were observed (Table 7.3).

Table 7.3. Mean number of cues and concerns per consultation

	Mean	**Standard deviation**	**Range**
Total number of cues and concerns	1.81	2.4	0 - 13
Total number of cues	1.08	1.69	0 - 8
Number of concerns	0.73	1.2	0 - 8
Number of cue a	0.23	0.55	0 - 3
Number of cue b	0.65	1.08	0 - 5
Number of cue c	0.03	0.16	0 - 1
Number of cue d	0.15	0.41	0 - 2
Number of cue g	0.02	0.19	0 - 2

No instance of cue e and f were observed

There were no significant correlations between IMD decile and number of cues and concerns, elicitation of cues and concerns, consultant's responses to cues and concerns, type of cues, and proportion of concerns to cues. However there was a significant positive correlation between IMD decile and length of consultation, r = .288, $p < .01$. When length of consultation was controlled for using Pearson's partial correlation there was a significant negative correlation between IMD decile and number of cues and concerns, r = -.221, $p < .05$. There was also a positive correlation between IMD decile and time to first cue or concern which approached significance, r = .218, p = .077 (Table 7.4).

Table 7.4. Correlation coefficients and p values for IMD deciles

	R	***P***
Number of cues and concerns	-.004	.97
Number of patient elicited cues and concerns	.072	.456
Number of consultant elicited cues and concerns	-.059	.543
Time to first cue or concern	.218	.077
Number of explicit reduce space responses	.03	.756
Number of explicit provide space responses	-.083	.389
Number of non-explicit reduce space responses	.004	.97
Number of non-explicit provide space responses	.055	.566
Appointment length	.288	<.01
Number of cue a	-.091	.346
Number of cue b	.02	.836
Number of cue c	-.05	.603
Number of cue d	-.074	.445
Number of cue g	.072	.456
Proportion of concerns to cues	.009	.943

IMD decile of 1 indicates the highest level of deprivation, while 10 indicates the lowest level of deprivation. Thus a positive correlation would suggest that, for example, patients from less deprived areas have longer appointments.

7.4 Discussion

7.4.1 Summary of findings

This study found that there were no significant differences by IMD decile in terms of the number and type of cues and concerns expressed by patients, whether the cues and concerns were elicited by the patient or consultant, or the consultant's responses. This contradicts my hypothesis that patients from more deprived IMD decile areas would raise fewer cues and concerns.

7.4.2 Comparison with previous literature

My findings are also in contrast to the findings of Verlinde et al's (2012) systematic review on SES and doctor-patient communication. As I described in section 7.1, they found that low SES patients asked fewer questions, were less likely to express their opinions or emotions, and were less likely to volunteer information unprompted during consultations, as well as receiving less information and rapport building from doctors (Verlinde et al., 2012). However that review did not include studies which measured SES using area-level deprivation. This suggests that perhaps area-level deprivation has little impact on doctor-patient communication, with individual-level SES variables having a greater effect.

When I controlled for consultation length, however, there was a significant negative association between IMD decile and the number of cues and concerns expressed. Initially it may seem that low SES patients expressed more cues and concerns, however due to my finding that low SES patients expressed their first cue or concern sooner in their consultations, it seems that actually high SES patients had longer consultations with more rapport-building and discussion while low SES patients were quick to express their concerns with relatively little small-talk, which would

not have been captured by the VRCoDES. This is supported by findings from Siminoff et al. (2006) that doctors spend more time building rapport with patients higher up the socioeconomic gradient (Laura A Siminoff et al., 2006). This suggests that SES differences in doctor-patient communication may be more complex than originally thought, and requires more in-depth research to better understand what takes place during interactions between patients and doctors in consultations. I address this gap in my next study, which is outlined in Chapter 8.

7.4.3 Implications

Given that the PCI was used in most (98 of 110) of the consultations, it is also possible that the lack of difference in raising concerns was because the PCI was effective in reducing SES differences. The PCI may have enabled low SES patients to raise as many concerns as high SES patients, however due to the lack of a control group it is difficult to determine if this is indeed the case.

7.4.4 Limitations

This study has a number of limitations. Firstly only 110 audiotapes were analysed, therefore the sample size may have been too small to detect significant differences. A post-hoc power calculation was carried out using G Power after the study had ended. It determined that in order to detect a medium effect size (0.3) the study had sufficient power (95%), however it did not have sufficient power to detect a small effect size (0.1, 28% power). This may potentially explain the lack of significant findings. If the effect size is small then it may have been detected with a larger sample. For example time to first cue or concern approached significance, suggesting that low SES patients raised concerns sooner in their consultations than high SES patients, but with a larger sample size it may have been significant.

However because this was data which had been collected for another study which had already ended, there wasn't anything I could do to increase the sample size. Secondly only one consultant participated in the study. As I described in Chapter 4, doctors can vary in their preferred style of communicating with patients, therefore the results may have been different if another consultant had participated.

7.5 Conclusion

In conclusion, my study suggests that area-level deprivation may have relatively little impact on doctor-patient communication in head and neck cancer follow-up clinics, in comparison to individual-level SES variables. It is also possible that consultations with low SES patients are characterised by less small-talk and rapport building. It seems that SES differences in doctor-patient communication may be more complex than originally thought, requiring more in-depth research. Therefore I addressed this gap in my next study (Chapter 8) by observing and audiotaping head and neck cancer follow-up consultations, and conducting qualitative interviews with patients, measuring SES using IMD as well as a range of individual-level SES variables.

Chapter 8: What are the underlying reasons behind socioeconomic differences in doctor-patient communication in head and neck oncology review clinics?

8.1 Introduction

The previous study outlined in Chapter 7 found that there was no association between area-level deprivation and raising of concerns during head and neck cancer consultations. This could be because individual-level SES variables have more influence over doctor-patient communication, or the measure of communication which I used (Verona Coding Definitions of Emotional Sequences, section 4.8.2.2) did not capture differences in rapport building. Given that previous studies have found SES differences in various doctor-patient communication behaviours (Rademakers et al., 2012; Laura A Siminoff et al., 2006; R. L. Street, 1992; Verlinde et al., 2012; S. Willems et al., 2005) (sections 4.3.6.4 and 4.4.1.4), and that area-level and individual-level SES measures reflect different aspects of material and social deprivation which may affect the doctor-patient interaction (Chapter 3), I decided to qualitatively explore the doctor-patient interaction in more depth using a range of SES variables and communication behaviours. Therefore the aim of this study was to explore how and why SES is associated with differences in doctor-patient communication. This was achieved by observing head and neck cancer review clinic appointments and exploring patient perspectives and experiences via follow-up interviews.

Given the findings on SES differences in doctor-patient communication (sections 4.3.6.4 and 4.4.1.4), it is possible that the poorer quality of life reported by low SES head and neck cancer patients (Ghazali et al., 2013; Rylands et al., 2016a, 2016b; Woolley et al., 2006) (see section 3.3.1) may be partly due to these differences in communication behaviours. Because low SES patients participate less actively in

medical consultations and are less involved in the consultation by their physician (Verlinde et al., 2012; S. Willems et al., 2005), they may be less likely to report concerns to a health care professional. If a healthcare professional is not informed then these concerns may not be addressed and subsequently contribute to worse quality of life. Therefore understanding how and why SES differences in communication occur may be key to improving quality of life for low SES patients.

A number of theories have been proposed to explain SES differences in health and doctor-patient communication. For example, status characteristics theory is the theory that perceived differences in social status influence how much both patient and doctor actively participate in the consultation, and how much both parties value the other's contributions. Social status is determined by specific status characteristics (e.g. expertise, qualifications, and other skills valued by the social group) and diffuse status characteristics (e.g. SES, ethnicity, gender). When an individual's status is high more expectations are placed on them, they are given more opportunities to participate, they participate more, and their participation is more valued by other parties than individuals who are perceived to be lower status (Berger, Rosenholtz, & Zelditch Jr, 1980; Peck & Conner, 2011). Thus, SES differences in communication may occur because low SES patients are perceived to have a lower status.

Another theory is lay theories of social class, which states that whether low SES individuals believe that their social status is biologically determined and unchangeable influences their physical health and emotional wellbeing. Belief that an individual's SES is biologically determined and cannot be changed is an essentialist theory, whereas a nonessentialist theory is that SES is not biologically determined and can be changed. Low SES individuals who hold essentialist theories about SES may experience more shame, anxiety and negative affect than those who

do not, which may impact their health long-term through fatalism (Tan & Kraus, 2015). Therefore, SES differences in communication may be due to essentialist beliefs about SES causing fatalism and negative affect in low SES patients.

The final theory is Maslow's hierarchy of human needs, which states that there are five types of needs within a hierarchy. The most basic needs are physiological, such as food and shelter. Only once those needs are met, can the individual strive for the next type of needs which are financial security and healthcare. After that is the need to belong to a particular social group or community. Next is the need for self-esteem and social status. Finally, once all of these needs have been fulfilled the individual can pursue self-actualisation, which is the desire for self-fulfilment (Maslow, 1943; van Lenthe, Jansen, & Kamphuis, 2015). Low SES patients may struggle to fulfil the more basic needs in the hierarchy due to problems with money and housing, therefore they cannot prioritise things such as active involvement in their healthcare.

However none of these theories have been explored within the context of healthcare communication with head and neck cancer patients. Reasons behind SES differences in doctor-patient communication have not yet been studied with this population.

Research question: How and why does the doctor-patient interaction differ by patient SES in head and neck cancer consultations?

Aims:

- To explore the preferred and experienced patient participation behaviours of individuals diagnosed with head and neck cancer, and how and why these differ by SES.

- To qualitatively analyse SES differences in the observed interactions which take place during head and neck cancer follow-up appointments.
- To explore which aspects of SES appear to be important in influencing the doctor-patient interaction.

8.2 Methods

8.2.1 Setting

Ethical approval was obtained from the National Health Service (NHS) Research Ethics Committee (North West - Haydock), reference 16/NW/0474. NHS research governance approvals were obtained prior to commencing the study (Appendix 2).

The study was conducted at Aintree University Hospital. Patients were recruited from the head and neck cancer review clinics of 5 male Consultant Surgeons, 4 of whom were Ear, Nose and Throat (ENT) specialists, and the final consultant was a Maxillofacial Unit (MFU) specialist. At the beginning of the study only 4 consultants were involved, however a few months into the study one of the ENT consultants retired. Therefore the consultant who took on the retired consultant's patients was brought into the study to ensure that sufficient patients could be recruited within the limited time-frame.

8.2.2 Participants

The inclusion criteria were that patients must be 18 years of age or older, and 12 to 24 months post-treatment for head and neck cancer. Exclusion criteria consisted of cognitive impairment which would hinder the conduct of interviews, requirement of an interpreter for healthcare consultations, and the consultant judging that the patient is at risk of being too distressed for interview. In addition, four patients declined to

take part in the study due to severe speech problems. Cognitive impairment was determined by screening patient records or as judged by the consultant.

8.2.3 Recruitment

Patient SES was measured using Indices of Multiple Deprivation (IMD) deciles (*The English Indices of Deprivation 2015*, 2015), as well as age leaving formal education, highest qualification, occupation, and employment status. I attempted to recruit patients from a range of socioeconomic backgrounds in order to compare data by patient SES. I did this by collecting data on patient IMD deciles before approaching them to participate in the study. After a few weeks of recruitment we excluded patients living in the Isle of Man due to practical issues with conducting interviews, as well as the absence of IMD scores for such patients.

Using the inclusion and exclusion criteria a Clinical Trials Nurse identified eligible patients from patient records, and then provided me with a list of these patients and the date and time of their next appointment at the head and neck clinic. I approached eligible patients in the waiting room prior to their appointment and explained the study to them before asking them if they would like to participate in the study that day. They were given an information sheet (Appendix 6) and if they wished to take part, were asked to sign a consent form (Appendix 5). I asked them whether they wished to be interviewed in their own home, over the phone, or at the hospital, and organised a time and place which was convenient for them to be interviewed a few days after their appointment.

Ideally patients would have been given more time to consider the study before consenting. The approach to recruitment was a balance between the benefits of using a Clinical Trials nurse to identify suitable patients from the clinical appointments for

that day using inclusion and exclusion criteria (which removed the need for a researcher to have access to confidential medical records) – against the downsides of approaching the patients at the time of visiting for their appointment. Additional clinical time to support the research was limited (limiting the extent of capacity of staff to go through appointment schedules for patients in advance, give personal details including addresses in order to send an information sheet and consent form in advance). So a pragmatic approach was taken – and the participant eligibility and recruitment were undertaken at the same time of attendance.

Information on patient IMD deciles, age, gender, and primary treatment for their head and neck cancer were obtained by the Clinical Trials Nurse from patient records. Patients' age leaving formal education, highest qualification, occupation as classified by the Office for National Statistics Standard Occupational Classification (ONS SOC), and employment status were obtained by asking patients for this information at the end of their interviews.

There are 10 IMD deciles, with decile 1 being the most deprived and decile 10 being the least deprived. In addition there are 9 ONS SOC major groups, with 9 being the lowest in the hierarchy (low SES) and 1 being the highest in the hierarchy (high SES) in terms of skill level and content.

Patients were classed as low SES with regards to education if they left formal education at 16 years old or earlier, or if their highest qualification was GCSE or equivalent, or lower. Patients were classed as low SES with regards to occupation if they were in ONS SOC major groups 5 – 9.

SES was categorised as low or high, separately for both education and occupation. Where both education and occupation indicated that participants had an either a low

or high SES status (in the results, a descriptor of 'low SES' etc was given and reported). Where the categorisation for education and occupation was contradictory – the specifics of the measure was used to maximise the transparency of the reporting of results e.g. low SES education.

8.2.4 Sampling and sample size

I used purposive sampling when recruiting patients for this study, initially aiming for around 40 participants (about 10 patients per Consultant) depending upon when saturation of data had been reached. Purposive sampling is the non-random selection of participants based on characteristics they possess which are relevant to the research question (Etikan, Musa, & Alkassim, 2016). Ritchie et al. (2013) advise that no more than 50 participants should be recruited for a qualitative study, as the aim of qualitative methods is to conduct an in-depth analysis on a small sample (Ritchie, Lewis, Nicholls, & Ormston, 2013). However a smaller sample size was recruited as data analysis was performed while data collection was ongoing, ending recruitment once no more new themes emerged during analysis of interview and consultation data (data saturation). Qualitative studies in the field of head and neck cancer have used similar sample sizes (Isaksson, Salander, Lilliehorn, & Laurell, 2016; McGrory, 2011; Olver, Eliott, & Koczwara, 2014).

In total, 36 patients consented to participate in the study and had their appointment observed and audiotaped, however only 32 were interviewed. Of the remaining 4 patients, 1 explicitly withdrew from the study after being informed during their appointment that their cancer may have returned, and 3 could not be contacted for interview following their appointments despite repeated attempts to contact them. Therefore, there were 68 data sources in total.

8.2.5 Thematic analysis

Patient interviews were analysed using thematic analysis (Braun, Clarke, Hayfield, & Terry, 2019) to identify patterns in actual and preferred communication between consultants and patients, and how these might differ across the socioeconomic gradient. Thematic analysis was chosen as the method of analysis because I wished to identify and compare patterns of communication within my data across the socioeconomic gradient.

The aim of thematic analysis is to identify, analyse and report themes within data, while organising and describing the data set in rich detail (Braun & Clarke, 2006). Some researchers argue that it is an accessible and theoretically flexible approach to analysing qualitative data, particularly for those who have less experience with qualitative research (Braun & Clarke, 2006). It was originally conceptualised as an evolution from the more quantitative content analysis (Braun et al., 2019).

This analysis involved identifying and listing relevant codes, followed by grouping together data which fits under each code. Codes are then combined into themes and sub-themes, which together form a comprehensive account of participants' experiences (Aronson, 1995).

Coding occurred until new data no longer added anything new to the analysis (data saturation). Initial themes were identified and discussed with a multidisciplinary team of three academic supervisors. Data collection and analysis occurred simultaneously so that the researcher could achieve theoretical sensitivity (codes and categories were developed from the data not pre-existing concepts) to a degree, therefore the topic guide changed throughout the study. The software NVIVO 10 was used to aid this analysis.

Status characteristics theory (Peck & Conner, 2011), lay theories of social class (Tan & Kraus, 2015) and Maslow's hierarchy of human needs (Maslow, 1943; van Lenthe et al., 2015) were used as a starting point in the analysis of the interviews, however it was not confined to these theories.

Some initial themes included patients and clinic staff apologising, patients showing gratitude, patients taking responsibility for various aspects of their healthcare, as well as time pressures, and patients feeling rushed or perceiving consultants as being busy. However as more data was gathered, these themes were exchanged for, or combined with, ones which fit the data better. An example of my early coding scheme from the beginning of the project, including some of these initial themes, can be found in Appendix 11.

I did not check my coding or themes and subthemes with participants. This lack of triangulation is a limitation, as it would have improved my themes and removed any inaccurate coding. However the use of data from appointments with the interviews was a useful way of checking participants' accounts of their appointments.

8.2.6 Extra analysis

After analysing the data using thematic analysis, it was determined that humour was a key sub-theme which emerged from this study. Therefore I decided to look through the appointment transcripts and count the number of jokes between patients and consultants to see if this differed by patient occupation.

Another key sub-theme was small-talk, therefore I decided to look at the length of each appointment (as recorded by my digital audio-recorder) and calculate the median, standard deviation, and interquartile range for each IMD decile. This was to see if there was a link between IMD status and appointment length.

8.2.7 Interviewing

When deciding whether to conduct the interviews face to face or over the phone, a review of the literature on the costs and benefits of both methods indicated that it would be best to give patients the choice to ensure their comfort and convenience (Knox & Burkard, 2009; Novick, 2008; Opdenakker, 2006).

Therefore patients were offered to be interviewed over the phone, at their home, or at a quiet room in Aintree Hospital's Clinical Research facility. Two patients even requested interviews to take place in cafes in the city centre, as it was close to their workplace. One patient requested the interview took place at the University of Liverpool. It's interesting to note that most patients (22) requested to be interviewed over the phone. The average length of face to face interviews was 53 minutes 26 seconds, whereas the average phone interview lasted 45 minutes 2 seconds. While it does seem that face to face interviews were longer, this is only by around 8 minutes on average. Example transcripts of a face to face interview and a telephone interview can be found in Appendices 9 and 10.

Typically interviews took place 2 or 3 days after the patient's appointment, however one interview took place 3 months after the patient's appointment as they were unexpectedly admitted to hospital for a few weeks and felt that they needed some time to recover before participating in an interview.

The fact that most of the interviews took place over the phone may have had some impact on my findings. When interviewing over the phone I could not make note of body language and other nonverbal behaviours which may have enriched my data. However participants who chose to be interviewed over the phone may have felt uncomfortable being interviewed in person, therefore the data gained from these

interviews may not have been as rich if I had insisted on interviewing them in person.

8.2.8 Observation

Appointments were observed and audiotaped in order to gather more information on the verbal and nonverbal behaviours which took place as part of the doctor-patient interaction. This data was used to tailor topic guides to each individual patient, so that I could ask patients about specific things which happened during their consultations. It was also useful in comparing patient views expressed during interviews, with what actually happened. An example topic guide can be found in Appendix 3.

8.2.9 Transcription

The first few appointments and interviews were transcribed by me in order to immerse myself in the data and to help me code the data and generate some initial themes. However for the majority of the appointments and interviews I used a transcription service in order to save time and concentrate on coding and refining my themes and subthemes. Ideally I would have transcribed all, if not most, of these myself in order to immerse myself in the data even more and potentially find themes and codes which I would not have otherwise. However there were a total of 68 audio-recordings to transcribe, which would have taken a considerable amount of time to do by myself.

8.2.10 Reflexivity statement

I am aware that as a researcher my previous experiences and personal characteristics may influence my interactions with participants and analysis of the data. As someone who has grown up in a middle-class household, the lens through which I view

participants' experiences and interactions was likely to be very different to those with a different upbringing.

My interpretation of consultants' behaviours was likely affected by my role as a non-clinician in this study, however some patients seemed to think that I was a clinician. This may have affected their interactions during observed appointments and what they said during their interviews.

In order to test whether my interpretations were biased, I checked my interpretations with participants during interviews. I also involved my supervisors in my analysis.

8.3 Results

Of the 36 patients who participated, most were men (n=24, 66.7%), with the most common primary treatment being surgery alone (n=13, 36.1%), closely followed by chemoradiotherapy alone (n=10, 27.8%). Average age was 64.9 years. Of my sample, 36% of participants lived in the 10% most deprived areas of the country (IMD decile 1), however there was nonetheless a spread of participants across the SES gradient with regards to education and occupation. Table 8.1 summarises the characteristics of the patients who were recruited into the study.

Table 8.1. Summary of patient characteristics

Patient	Age	Gender	IMD decile	Age leaving formal education	Highest qualification	ONS SOC major group	Occupation	Employment status	Consultant	Appointment length (minutes)	Interview context	Primary treatment	Overall SES
1	51	Male	9	35	Postgraduate	6	Ambulance technician	Employed	1	11:25	Phone	Surgery	High SES education, low SES occupation
2	68	Male	2	*NA*	*NA*	*NA*	*NA*	*NA*	2	6:20	*Interview not completed*	Chemoradiotherapy	*Insufficient information*
3	58	Female	3	16	Undergraduate	7	Nursery advisor	Employed	2	8:27	Cafe	Chemoradiotherapy	High SES education, low SES occupation
4	75	Female	1	15	None	6	Carer	Retired	2	9:27	Phone	Radiotherapy	Low SES both domains
5	74	Female	8	16	GCSE or equivalent	7	Shop assistant	Retired	4	8:21	Home	Chemoradiotherapy	Low SES both domains
6	62	Male	1	15	None	5	Painter and decorator	Sick leave	2	10:02	Phone	Surgery and radiotherapy	Low SES both domains
7	76	Female	3	15	None	6	Carer	Retired	1	6:19	Phone	Surgery	Low SES both domains
8	63	Male	4	16	GCSE or equivalent	5	Auto-electrician manager	Employed	1	7:06	Phone	Surgery	Low SES both domains
9	57	Male	9	16	Undergraduate	1	Police detective	Retired	3	6:37	Phone	Surgery and radiotherapy	High SES both domains
10	56	Male	1	16	GCSE or equivalent	3	Management at council (former army)	Retired	2	5:10	Hospital	Surgery and radiotherapy	Low SES education, high SES occupation
11	62	Male	1	15	GCSE or equivalent	4	Cost control	Retired	4	8:55	Hospital	Surgery	Low SES education, high SES occupation
12	60	Male	4	22	Undergraduate	2	Microbiologist	Retired	3	6:01	Cafe	Surgery	High SES both domains

13	57	Female	4	15	None	5	Managing pubs	Retired	4	9:30	Phone	Chemoradiotherapy	Low SES both domains
14	59	Male	1	16	None	4	Manager at job centre	Employed	3	9:21	Phone	Chemoradiotherapy	Low SES education, high SES occupation
15	73	Male	4	15	None	8	Factory worker	Retired	1	6:54	Phone	Surgery	Low SES both domains
16	43	Female	9	20	A level or equivalent	5	Maintenance manager	Employed	4	12:05	Phone	Surgery	High SES education, low SES occupation
17	89	Male	5	15	None	1	Owned newsagents	Retired	4	9:47	Home	Radiotherapy	Low SES education, high SES occupation
18	59	Male	1	16	GCSE or equivalent	6	Nursery nurse	Unemployed	3	4:57	Hospital	Transoral laser resection	Low SES both domains
19	69	Male	10	15	None	8	Train driver	Retired	1	7:34	Home	Chemoradiotherapy	Low SES both domains
20	56	Female	2	17	A level or equivalent	8	Assembling electronics	Employed	3	6:38	Phone	Radiotherapy	High SES education, low SES occupation
21	70	Female	1	15	None	6	Teaching assistant	Retired	3	6:56	Home	Radiotherapy	Low SES both domains
22	80	Female	7	*NA*	*NA*	*NA*	*NA*	*NA*	5	8:21	*Interview not completed*	Radiotherapy	*Insufficient information*
23	48	Female	6	16	GCSE or equivalent	1	European managing director	Employed	1	6:40	Phone	Surgery	Low SES education, high SES occupation
24	56	Male	1	16	GCSE or equivalent	8	Printing floor worker	Employed	5	6:39	Phone	Chemoradiotherapy	Low SES both domains
25	69	Male	6	16	GCSE or equivalent	1	Owned computer business (former police officer)	Retired	1	5:08	Phone	Surgery	Low SES education, high SES occupation

26	63	Male	1	17	None	6	Care assistant	Retired	5	1:27	Phone	Chemoradiotherapy	Low SES both domains
27	64	Male	1	*NA*	*NA*	*NA*	*NA*	*NA*	3	9:54	*Interview not completed*	Radiotherapy	*Insufficient information*
28	40	Male	1	*NA*	*NA*	*NA*	*NA*	*NA*	4	8:17	*Interview not completed*	Chemoradiotherapy	*Insufficient information*
29	63	Male	1	20	A level or equivalent	5	Maintenance engineer	Employed	4	2:57	Phone	Surgery	High SES education, low SES occupation
30	69	Male	5	16	GCSE or equivalent	2	Computer software developer and consultant	Retired	3	18:04	Phone	Chemoradiotherapy	Low SES education, high SES occupation
31	70	Female	9	22	Postgraduate	2	Social worker	Retired	1	4:07	Phone	Surgery and chemoradiotherapy	High SES both domains
32	91	Male	7	17	None	1	Director of accounting firm	Retired	4	6:38	Phone	Surgery	Low SES education, high SES occupation
33	75	Male	4	15	None	3	Indent agent	Retired	3	9:48	University	Surgery and radiotherapy	Low SES education, high SES occupation
34	67	Male	1	15	None	8	Long distance lorry driver (former army and navy)	Retired	3	7:52	Phone	Surgery and radiotherapy	Low SES both domains
35	81	Male	3	15	None	8	Taxi driver	Retired	5	3:05	Phone	Surgery	Low SES both domains
36	64	Female	8	15	GCSE or equivalent	6	Nursery nurse	Retired	4	23:23	Phone	Surgery and radiotherapy	Low SES both domains

Some of the patient characteristics in Table 8.1 include the SES measures I used: age leaving formal education, highest qualification, IMD decile, and Office for National Statistics Standard Occupational Classification (ONS SOC) major group.

Of the 32 patients who were interviewed, 15 were classed as low SES for both education and occupation, 3 were high SES for both domains, 5 were high SES education but low SES occupation, and 9 were low SES education but high SES occupation. Given that sometimes classification into high/low SES was not consistent across the two SES domains of education and occupation, which is a finding in itself, when reporting supporting quotations I have given both domain classifications.

Table 8.2 summarises the characteristics of the consultants involved in the study.

Table 8.2. Summary of consultant characteristics

Consultant	Department	Gender
1	Ear, Nose and Throat	Male
2	Ear, Nose and Throat	Male
3	Ear, Nose and Throat	Male
4	Maxillofacial Unit	Male
5	Ear, Nose and Throat	Male

A number of themes emerged from the interviews conducted with patients with regard to SES differences in doctor-patient communication, and why these differences occur. There were three main themes: ‘Relational talk’, ‘Active or passive participation’ and ‘Preferences for involvement’. There were also seven sub-themes in total, with ‘The use of humour’ and ‘Small-talk’ belonging to the theme ‘Relational talk’. The sub-themes ‘Education and occupation as a frame of reference’, ‘Patients with an agenda’, and ‘Responsibility for obtaining information’ belonged to the theme ‘Active or passive participation’. The sub-themes ‘Defining

involvement in decision-making' and 'Stoicism' belonged to the theme 'Preferences for involvement'. A summary of the themes can be found in Table 8.3.

Table 8.3. Overview of themes and sub-themes

Main Themes	Sub-themes
Relational talk	The use of humour
	Small-talk
Active or passive participation	Education and occupation as a cultural frame of reference
	Patients with an agenda
	Responsibility for obtaining information
Preferences for involvement	Defining involvement in decision-making
	Stoicism

8.3.1 Theme 1 – Relational talk

8.3.1.1 Sub-theme 1 – The use of humour

I observed that the tone of consultations was warmer and more familiar with high SES patients. Doctors were friendly and talkative towards patients from higher occupational classes, spending time to recognise and build rapport in their relationship. The use of humour in these interactions was particularly characteristic, with the consultant usually initiating the joke. Below are some examples of jokes during the both opening and farewell sequences of the consultation:

> ***Patient**: "Thank you very much"* (Shake hands, both sitting).
>
> ***Consultant**: "So see you in 3 months."*
>
> ***Patient**: "Alright, thank you."*
>
> ***Consultant**: "Yeah, so for the person recording – he is very grateful he said!!!"*
>
> ***Patient**: "I am extremely grateful."*
>
> ***Consultant**: "I know you are."*

***Patient**: "Superb expertise."*

***Consultant:** "Cheers mate. I know you mean that by the way. Thank you very much."*

***Patient**: "Thank you."*

Patient 25, IMD 6, ONS 1, GCSE or equivalent, Consultant 1, Consultation

***Nurse:** "Sorry for the delay, come on in."*

***Consultant:** "Hello. Long-time no see."* (Patient sits down and both shake hands)

***Patient:** "Yes"*

***Consultant:** "You've grown a beard like me."*

***Patient:** "Yes but I can't grow it down here"* (All laugh)

Patient 9, IMD 9, ONS 1, Undergraduate, Consultant 3, Consultation

***Consultant:** "Right. So they are recording, as you know that."*

***Patient:** "Yes, that's fine."*

***Consultant:** "So don't say anything that we are not supposed to say! Erm… laughs… she just takes notes as well. She sits there…"*

***Patient:** "Oh he's a lovely person…!"*

***Consultant:** "You're lovely too. You're one of my favourite patients!"*

Patient: *"…he's treated me so well…!"*

Consultant: *"Thank you so much. Laughs. You all right."*

Patient: *"I'm fine."*

Patient 23, IMD 6, ONS 1, GCSE or equivalent, Consultant 1, Consultation

In contrast, for lower SES patients the farewell sequence within consultations was shorter and much more formal:

Consultant: *"Alright Mr (patient)….. I can't see anything* (Facing patient, making eye contact). *We'll just get the scans to look at the tissues inside. I think, I think it's just the result of the surgery of the radiotherapy causing scarring in there, but we will get the scan and it will also act as a baseline for us. Now, I'll see you back on the 7th June."*

Patient: *"Alright, thanks very much."*

Consultant: *"Alright, take care now.* (Shake hands both sat down, Consultant lifts up a bit off his chair). *Bye."*

Patient: *"Bye."*

Patient 6, IMD 1, ONS 5, No qualifications, Consultant 2, Consultation

Consultant: (Finishes endoscopy) *"That all looks great."*

Patient: *"Good."*

Consultant: (Standing next to patient, who is still sitting) *"So you just have a bit of scarring round the back, which we have known from before but we*

biopsied the area and it's all fine. So we just keep following you up. We will see you again in three months' time."

Patient: *"Good, good."*

Consultant: *"Any questions otherwise?"*

Patient: *"No."*

Patient 35, IMD 3, ONS 8, No qualifications, Consultant 5, Consultation

Consultant: (Eye contact) *"Big milestone was July cause we were 2 years up alright and a vast majority of people who get recurrence it happens in the first 2 years, so we are not out of the woods yet but it was a big milestone so that was good."*

Patient: *"Okay."*

Consultant: *"Is that alright. I am going to leave your GP to keep an eye on your thyroid hormone levels, I am not going to have too many chefs spoiling the broth so to speak okay."*

Patient: *"Okay. Thank you."*

Consultant: *"Good, nice to see you."*

Patient: *"Thank you"* (Shake hands, patient standing, Consultant sitting).

Consultant: *"Take care."*

Patient: *"Thank you."*

Patient 21, IMD 1, ONS 6, No qualifications, Consultant 3, Consultation

One contrast in formality which can be seen here, is when the consultant addresses Patient 6 as 'Mr…', but Patient 25 is referred to as "mate" following their joke.

Previous research has found that individuals use humour and teasing to create power and solidarity within an interaction, with teasing particularly used in gender concordant interactions (Hay, 2000). In total there were 103 jokes between patients and Consultants across 32 observed appointments (excluding the four interactions where I did not have information on patient education or occupation). Of these jokes, 50 took place during consultations with patients from high status occupations (median jokes per consultation = 3, IQR = 5), while 53 jokes were observed with patients in lower ONS occupations (median jokes per consultation = 2, IQR = 3.25).

8.3.1.2 Sub-theme 2 – Small-talk

Consultants seemed much colder when interacting with patients from lower SES backgrounds, providing very little space for patients to speak and not attempting to initiate or encourage rapport in the same way. Consultants did most of the talking, much of which was centred around the consultation with very little small-talk or attempts at humour. Below are some examples of small-talk in the opening sequence, where the consultant drives the level of conversational familiarity and the patient responds appropriately:

> ***Consultant:*** *"No problems?"*
>
> ***Patient:*** *"No I feel great now. I feel back to normal."*
>
> ***Consultant****: "Yes? Still doing charity races and things like that?"* (Eye contact, sat closer)

Patient: *"I did erm… I did a hike for Macmillan Cancer in June… so I am minus about 6 toe-nails at the moment because it's a marathon hike in the Lake District. So it took 14 hours."*

Consultant: *"Oh right. Not the right shoes and all that?"*

Patient: *"No… I had, it was just, you know, the terrain."*

Patient 23, IMD 6, ONS 1, GCSE or equivalent, Consultant 1, Consultation

Consultant: *"You're, are you with the other side now aren't you?"*

Patient: *"I am yes."*

Consultant: *"You're a man of leisure."*

Patient: *"A man of leisure. I seem to be doing more now than I did when I was working though."*

Consultant: *"Oh yeah."*

Patient: *"I'm finding time to do all the things I couldn't do when I was working."*

Consultant: *"What do you to amuse yourself then?"*

Patient: *"Well I've got a caravan down in Wales in Llangollen so I spend quite a bit of time down there. Do quite a bit of fishing, remember I was telling you? Erm… I do quite a bit of DIY and stuff around the house so… there's always stuff to do."*

Patient 12, IMD 4, ONS 2, Undergraduate, Consultant 3, Consultation

In contrast, here are some examples of an opening sequence where the discourse with a low SES patient is much more focused on the medical aspects of the consultation, than the relational aspects. Note that this was the same Consultant as observed in the interaction reported above.

Consultant*: "How are you?"*

Patient*: "Fine."*

Consultant*: "Good. No problems?"*

Patient: *"No none at all."*

Consultant*: "That's what we like to hear. Shall we have a little look down?"*

Patient*: "Yeah yeah."*

Patient 18, IMD 1, ONS 6, GCSE or equivalent, Consultant 3, Consultation

Consultant: *"Right how are things?"*

Patient: *"Erm same as they were last time. It's erm…I still have trouble eating the same things, eating bread and stuff like that"* (Mumbling, has hands clasped in lap and makes little eye contact with Consultant. Silence while consultant prepares for physical exam).

Consultant: (Physical exam starts, Consultant speaks very quietly now) *"Just look up (inaudible) for me."*

Patient 4, IMD 1, ONS 6, No qualifications, Consultant 2, Consultation

Medical discourse is known to be a balance between institutional (e.g. medical) and socioemotional frame for talk (Ragan, 2014). Therefore the consultation can be divided into task (instrumental) talk and relational (small) talk (Ragan, 2014). I found that a lower proportion of the consultation was given to relational talk for low SES patients. This difference in proportion of time spent on small-talk could be partly due to differences in appointment lengths. Table 8.4 shows the mean appointment lengths for each IMD decile. Barring a few outliers, there seems to be a general trend in which patients from less deprived areas tend to have longer appointments. This is in line with results from my previous study (chapter 7, section 7.3), which found a significant positive correlation between appointment length and IMD decile.

Table 8.4. Mean appointment length by IMD decile

IMD decile	Median appointment length (minutes : seconds) [IQR]	Number of appointments	Standard Deviation
1	7:52 [4:11]	13	2:44
2	6:29 [0:09]	2	0:12
3	6:19 [2:41]	3	2:42
4	7:06 [2:36]	5	1:41
5	13:55 [4:08]	2	5:51
6	5:54 [0:46]	2	1:05
7	7:29 [0:51]	2	1:12
8	15:52 [7:31]	2	10:37
9	9:01 [5:35]	4	3:50
10	7:34 [0]	1	NA

IQR = Interquartile range

8.3.2 Theme 2 – Active or passive participation

I observed that low SES patients took a less active role in the consultation, with consultants taking more of a lead in the discussion and with such patients raising fewer concerns and new topics of discussion. This pattern was influenced by three factors: firstly by patients with knowledge and experience gained in higher education or in their occupation, using this to 'oil the wheels' of the interaction; secondly by higher SES patients coming into the consultation with their own agendas; and thirdly by lower SES patients viewing information provision as the consultant's responsibility, rather than it being their responsibility to obtain it.

8.3.2.1 Sub-theme 1 – Education and occupation as a cultural frame of reference

I found that patients made reference to their education and occupation in consultation interactions. More educated patients and those with an insight into the workings of the health service by virtue of their occupations, appeared to consciously apply this knowledge to help navigate the system, and to reduce the doctor-patient power difference. The quote below is from an interview with a patient who previously worked as a microbiologist in the NHS, and who clearly felt his background enabled a more equal partnership; facilitating a positive interaction in the consultation for the sake of the consultant's satisfaction with the appointment, and not just their own satisfaction:

> ***Patient:*** *"I know a lot of patients going in they are probably quite nervous when they go to see a Consultant like, you know what I mean, or any doctor, not just because of the illness but because of they see them as somebody quite powerful and very professional and very different. But having worked in that environment over the years I can converse with them much easier. I know*

the system I know how the system works and make it easier for myself and them as well."

Patient 12, IMD 4, Undergraduate, ONS 2, Consultant 3, Interview

This is in contrast with a patient with a manual occupation background (Patient 8), who was an auto-electrician working on motorway signage; who made reference to his occupation, but in a different way. Patient 8 made this reference to his occupation when talking about the extent to which he trusted the information and was reliant on the Consultant's superior knowledge and expertise. The patient takes a less opinionated and more passive stance than the patient who had a more professional occupational background, in recognition of their different domains of knowledge and expertise:

Patient: *"See I am in the motor trade as an auto-electrician and erm, mechanics, and so I am mechanically minded. So, so, I know if someone is saying something is right, then it's got longevity at least."*

Patient 8, IMD 4, GCSE or equivalent, ONS 5, Consultant 1, Interview

Another low SES patient (Patient 10) talks about his background in the army, and how he compares the information given at diagnosis to a 'battle plan'. He trusts the knowledge and expertise of the consultant, and knows what to expect from his cancer journey over the coming years.

"And it's laid out in type layman's rules…when they give me the documents and said about what the chances, and said… the first two years you're going to be up to erm… 25-40%... I like that, I like it like… 'cause I say, I'm an ex-solider, it's like a battle plan to a degree isn't it? You think right, get to the two year stage and hopefully that's the biggest, biggest, achievement once

you get to that you know, it's three years, and it's sort of downhill after that because you're gonna… you've got an 85% chance of living and in three years it's only going to get better to become 100% so…I do like that they do lay it out that way and say you know… you're gonna be on this five year plan hence… or cancer journey, whatever you want to say. You know what to expect and what's coming really."

Patient 10, IMD 1, GCSE or equivalent, ONS 3, Consultant 2, Interview

8.3.2.2 Sub-theme 2 – Patients with an agenda

I found that higher SES patients came to consultations with their own ideas about what they wanted to know and discuss; appearing very confident about raising any concerns they had about their quality of life. Interview data from Patient 3 illustrates this, as an example of a higher SES patient who consciously set out to make the most out of their follow-up appointment. Higher SES patients were observed to be less likely to be deterred from discussing their topic of interest, when they did not appear to be concerned that they would be made to feel stupid or that their concerns would be dismissed, and most stated that they asked about something at each visit.

Patient: *"Any concerns and you can bring anything up, I don't feel it's going to be a stupid question."*

Interviewer: "Yeah. So, there wasn't anything else which you wanted to ask but didn't get out?"

Patient: *"No, I generally have a question every time I go…(chuckles)…I generally bring something up."*

Interviewer: "You seem very comfortable to ask the questions you want?"

Patient: *"Yeah yeah I do, as I say in the past usually at every consultation that I have had I have asked something about some part of my mouth, throat, tongue…"*

Patient 3, IMD 3, Undergraduate, ONS 7, Consultant 2, Interview

This same patient pursues a concern during their appointment, despite being ignored by the Consultant initially.

Consultant: *"Any problems?"*

Patient: *"Erm no, er a niggling problem. Err just like when I'm breathing, it's like an irritation on the back of me throat like, you know like when you used to have croupe when you were a kid-"*

Consultant: *"Mmm* (Writing notes during problem presentation)."

Patient: *"-and you know that sort of wheezy breathe that doesn't have anything to do with anything. It just makes me want to clear me throat all the time.* (3 Second silence while consultant continues to write) *I don't know if it's the air or you know sensitive or…"*

Consultant: *"Any indigestion? Heartburn?"*

Patient 3, IMD 3, Undergraduate, ONS 7, Consultant 2, Consultation

In contrast low SES patients were more passive in their approach, and more reticent to raise emotional concerns during appointments. For example, Patient 7 describes waiting for the consultant to set the agenda, which was more focused on the instrumental aspect of the appointment.

Interviewer: "You mentioned your problems with swallowing to Mr (consultant) in the appointment?"

Patient: *"I didn't I thought I would wait for the outcome, get the camera down and I will wait for the outcome and then if it was that the cancer had progressed then I would tell him how I felt about it beforehand."*

Interviewer: "Yeah."

Patient: *"But I didn't mention it."*

Interviewer: "Okay, I think erm…you mentioned it a bit after he had given you the kind of…"

Patient: *"He said "All clear" and I said "Thank goodness for that"."*

Interviewer: **Laughs…**

Patient: *"That's all I said. I didn't say I had been worried or anything."*

Patient 7, IMD 3, No qualifications, ONS 6, Consultant 1, Interview

8.3.2.3 Sub-theme 3 – Responsibility for obtaining information

I found that higher SES patients actively sought information from the consultant, even outside of the consultation if they had forgotten to mention it. This is exemplified in this quote from Patient 3, high SES patients saw it as their responsibility to seek information, and if someone did not receive sufficient information then it was their fault.

Patient: *"Yeah…occasions erm…I have phoned up and said look I forgot to ask this or forgot to ask that, erm and I have done that with my doctor as well and someone phones me back or I phone back when they tell me to phone*

back or I get a letter or whatever. I think if you ask you will get the information."

Patient 3, IMD 3, Undergraduate, ONS 7, Consultant 2, Interview

Some high SES patients even took this one step further, and sought information about their condition on the internet. Patient 12 describes seeking information from journal articles about the efficacy of a medication he was taking for a different condition, in destroying cancer cells. He then brought these papers to the consultant as a possible explanation for why they did not find his primary cancer site following diagnosis. He describes information exchange as a two way exercise, in which not only patients receive information, but consultants can also obtain useful knowledge in their field.

Patient: *"Yes… and as I said before, if I don't get all the information, I request it when I meet him and even offer my own information as well. . . . So I… I printed off all these papers again, this is the second time I went in with loads of papers… and I said to Mr (consultant) about this drug. I had already told him I was on this drug and he didn't actually know much about that drug actually. I said, "did you know that drug has been used to treat head and neck cancers." He said, "No. Where did you get that information?" I said, "well I've got it all here printed off for you!" . . . So it has been a two-way exercise. So I have taught him a bit and he's taught me quite a lot. (laughs)"*

Patient 12, IMD 4, Undergraduate, ONS 2, Consultant 3, Interview

Whereas lower SES patients believed that it was the consultant's responsibility to provide them with any important information, as can be seen with Patient 6.

Interviewer: "Do you feel like you get enough information from them?"

Patient: *"Yes yeah."*

Interviewer: "Erm and do you find that you get reassurance as well?"

Patient: *"Yeah yeah. I mean especially with Mr (consultant), I mean he is straight with you."*

Interviewer: "Yeah."

Patient: *"I mean he won't try and kid you or nothing."*

Interviewer: "Mmm."

Patient: *"If he thinks there is something wrong he tells you he thinks there is something wrong."*

Interviewer: "Yeah."

Patient: *"Which I would sooner have it like that, I wouldn't like to think that they are holding things back you know."*

Patient 6, IMD 1, No qualifications, ONS 5, Consultant 2, Interview

8.3.3 Theme 3 – Patients' preferences

8.3.3.1 Sub-theme 1 – Defining involvement in decision-making

When patients were asked how involved they were in deciding cancer treatment and whether they were happy with that level of involvement, I found that there were SES differences in terms of how patients defined involvement. Low SES patients interpreted 'involved' as being fully informed of any decisions which the consultant made, as can be seen with Patient 6.

> ***Patient:*** *"Erm…well I expect to be 100% involved…You know if, say he was going to operate on me or things like that…I would like to be involved. You know I would want to know everything about it before it actually happened…And like I say I have only had the one operation you know when he took the tumours out and he explained everything about that you know before it got done and then after it had been done, the first time I seen him afterwards…He went through everything with me, he explained it all. He was very good he really is."*
>
> *Patient 6, IMD 1, No qualifications, ONS 5, Consultant 2, Interview*

These patients seemed uninterested in making decisions, and this was reflected in the consultations which I observed: Consultants made decisions for them, and they seemed happy with this.

In contrast, high SES patients seemed very interested in taking part in the decision-making process. Consultants facilitated this, discussing various options available so that the patient could make an informed decision. For example, Patient 3 talks about her discussion with the consultant when she was first diagnosed, in which they discussed two possible treatments. One of the treatments was currently undergoing a clinical trial.

> ***Patient:*** *"Yeah I like to be involved 'cause I like to know what is going on. Erm…I have always been explained to me why they are doing things and initially when the treatment was. When I was diagnosed and they said to me, 'Well there is two courses of treatment', he said 'There is the tried and tested one or there is a new erm…one that they are trialling'… But obviously it's*

not as, they do not know the results, so he said: 'What do you want to do?', he said 'It's got to be your decision'."

Patient 3, IMD 3, Undergraduate, ONS 7, Consultant 2, Interview

8.3.3.2 Sub-theme 2 – Stoicism

Stoicism is the endurance of pain or hardship without the display of feelings and without complaint. The degree of stoicism appeared to differ with SES, with those at the lower end of the spectrum preferring to deal with problems on their own rather than involving healthcare professionals or even friends and family. This in illustrated by data from Patient 13, who had an outlook on life that "*You just have to get on with it*."

Patient: *"But I keep it to myself, I don't say it to my daughter as I don't like to upset her, you know, worry her. I wouldn't like to worry her and she says to me "Have you got any pains? Don't forget to tell the doctors, tell them everything, write everything down." I say, "I'm Okay, Okay." I just keep on saying to myself that it's the chemo or the radio because a lot happens to the inside of your body so this is why this is happening and things like that and thinking about everything that he says to you and I just… you just have to get on with it."*

Patient 13, IMD 4, No qualifications, ONS 5, Consultant 4, Interview

This contrasted with higher SES patients who were keen to talk through any issues with Consultants in order to help them deal with these problems. They not only wanted to make the Consultant aware of their problems but also to understand them for themselves, as can be seen with Patient 12.

> ***Patient:*** *"I am comfortable like about expressing things, like you know what I mean like. I like to talk things through, I like to get to the very bottom of things. I like to get to understand it myself, like you know, because of my science, medical background I like to know and understand anything, you know what I mean? If there's something I don't know about, tell me more about it, I want to know."*
>
> *Patient 12, IMD 4, Undergraduate, ONS 2, Consultant 3, Interview*

Low SES patients on the other hand, appeared almost proud of delaying raising concerns or seeking help. One such patient very briefly mentioned swallowing problems in her appointment but vehemently denied it later:

> ***Patient:*** *"I am not a worrying type, if something happens in life get on with it, deal with it. That's how I am made."*
>
> *Patient 7, IMD 3, No qualifications, ONS 6, Consultant 1, Interview*

This stoicism seems to be an important part of their identity for low SES patients. For example, one patient spoke about it being passed down from their parents:

> ***Patient:*** *"And my mother was quite a strong woman. You know she, we were never mollycoddled as children and we were expected, they were loving parents but we were expected to err…to get on with it. As they had, they came from a different generation obviously. Which isn't a bad background to be perfectly honest, it's it's…I don't know it spells out to you what is important in life and what's the priorities. So I appreciated all that. And I think you do inherit some of that."*
>
> *Patient 14, IMD 1, No qualifications, ONS 4, Consultant 3, Interview*

8.4 Discussion

8.4.1 Summary of findings

Three key themes emerged from my data with socioeconomic differences in relational talk, active or passive participation, and patients' preferences during consultations. Sub-themes included humour, small-talk, responsibility, having an agenda in the consultation, involvement, stoicism, and using education and occupation as a frame of reference. These differences were by patients' education or occupation, while IMD status was not associated.

8.4.2 Comparison with previous literature

I found that consultants used humour more in interactions with high SES patients than with low SES patients. While various studies have been conducted on the role of humour in both clinical and non-clinical settings (Granek-Catarivas, Goldstein-Ferber, Azuri, Vinker, & Kahan, 2005; Hay, 2000; Pizzini, 1991), it seems that mine is the first study to compare the use of humour in consultations with patients by socioeconomic differences. Such studies suggest that humour can be used as a way of creating power and solidarity between the participants of an interaction (Hay, 2000; Pizzini, 1991). For example, Consultant 1's repeated jokes about the consultations being recorded may have been a way for him to cope with the discomfort of being recorded, while also identifying and reinforcing the researcher as an 'outsider' (Hay, 2000). It may be that consultants naturally create solidarity more with high SES patients, who are more similar to them in terms of cultural and social capital, than patients at the lower end of the socioeconomic gradient. Hay (2000) also identified that humour could be used to control individuals' behaviour, which was observed in one consultation where the consultant joked about breaking the

patient's fingers if she started smoking again. However this was not observed in any other consultations.

My finding that consultants engaged in less small-talk and rapport building with low SES patients is supported by other studies such as Siminoff et al (2006). They analysed the consultations of 405 newly diagnosed breast cancer patients with 58 Oncologists using the Roter Interaction Analysis System (RIAS, section 4.8.2.1), and found that Oncologists spent less time building rapport with patients who had lower levels of education (Laura A Siminoff et al., 2006). However unlike my study, the authors did not conduct follow-up interviews with patients after their appointments which gave depth to my findings.

My finding that patients from less deprived areas had longer appointments, is consistent with the findings from my previous study where there was a significant positive correlation between appointment length and IMD decile (Chapter 7, section 7.3). This may reflect the lack of relational talk which occurred between consultants and low SES patients, which we observed. Coupland et al., (1994) found that both patients and doctors worked to sustain the relational portion of the consultation which delayed the instrumental portion (Coupland, Robinson, & Coupland, 1994), however in our study this relational portion was lacking in consultations with low SES patients, instead prioritising the instrumental aspects of the consultation.

However what is interesting about my findings is that low SES patients seemed to want a brief consultation which gets 'straight to the point', without all of the relational talk which higher SES patients received. This is in contrast to the assumption which some other researchers hold, that low SES patients want more relational talk but do not receive it (Verlinde et al., 2012; S. Willems et al., 2005).

This finding has considerable implications for interventions aimed at improving care for low SES patients.

I found that low SES patients were more passive in their consultations through the way in which they used their occupation as a frame of reference that differed from high SES patients, letting the consultant set the agenda for the consultation, and placing the responsibility for information provision on the consultant. This passivity is in line with the findings of two systematic reviews on SES differences in doctor-patient communication, suggesting that low SES patients ask fewer questions and are less likely to express their opinion during consultations (Verlinde et al., 2012; S. Willems et al., 2005). However, as outlined in Chapter 5, the studies included in these reviews focus mainly on doctor behaviours with only a few of the included studies looking at patient behaviours. Therefore my study addresses this gap in the literature.

A study conducted in a hernia repair clinic using non-participant observation of 12 patients and interviews with 10 patients also found that their participants had a passive attitude towards information provision. They expected the clinic staff to provide them with any important information, which led patients to report being given insufficient information. However there is very little information on the SES of the participants of this study (Avis, 1994). One possible way of addressing patients' unmet information needs may be routine use of the Patient Concerns Inventory (PCI) in clinical practice. The PCI is a question-prompt list which allows patients to select what topics they wish to discuss with their consultant, prior to their appointment (see section 4.9.3.1). This is then used to streamline the consultation (S. N. Rogers & Lowe, 2014). Studies have found that it is feasible to use with both elderly patients and those with little education (Hatta et al., 2014; S. N. Rogers,

Audisio, et al., 2015), and currently a trial is being conducted to examine whether its long term use may improve patients' quality of life (S. Rogers et al., 2019).

The finding that low SES patients seemed to prefer to deal with problems on their own in private as a way of coping with their condition, is supported by previous research. For example, a study conducted with breast cancer patients found that low SES patients raised significantly fewer concerns during consultations with their Oncologist (Laura A Siminoff et al., 2006). Some studies have found that individuals from low SES backgrounds tend to expect negative outcomes, which can lead to hopelessness and chronic stress (Kristenson, Eriksen, Sluiter, Starke, & Ursin, 2004). They engage in more fatalism and avoidance, as opposed to instrumental coping behaviours such as talking through issues with their doctor, displaying lower perceived control over events (Caplan & Schooler, 2007; Westbrook, 1979). It seems that such patients in my study may not expect their quality of life to improve, which may be why they preferred not to talk to their consultant about any quality of life issues they were experiencing.

I also found that stoicism seemed to be an important part of low SES patients' identities. This is supported by studies which have found that low SES individuals present themselves as having persisted in the face of adversity as an important part of their identity, thus maintaining personal responsibility and avoiding being labelled as a victim (Bolam, Hodgetts, Chamberlain, Murphy, & Gleeson, 2003; Bolam, Murphy, & Gleeson, 2004).

Furthermore, low SES patients stated that they had not been involved in making decisions about their care, which they were content with. This is in line with previous studies which have found that individuals from low SES backgrounds were

less likely to seek information or have a preference for active involvement in decision-making (Arora & McHorney, 2000; Garfield et al., 2007; Lee, Ramirez, Lewis, Gray, & Hornik, 2012).

My finding that low SES patients defined involvement as being fully informed of decisions which the consultant made, is reflected in the literature. A study of frail elderly patients in Sweden found that patients had a similar definition of involvement, wanting information from healthcare staff even if their role in the clinical relationship was largely passive (Ekdahl, Andersson, & Friedrichsen, 2010). However this study did not report the SES of participants, therefore it is difficult to determine whether this perception was due to SES or some other variable such as age.

8.4.3 Implications

There are two systematic reviews which have looked at SES differences in doctor-patient communication, finding that low SES patients both receive more directive consultations from doctors, but also participate less actively themselves (Verlinde et al., 2012; S. Willems et al., 2005). One of their conclusions is that doctors provide low SES patients with less information because they mistakenly assume that such patients do not want as much information, however my findings challenge this. My study suggests that these doctors may be correct in their assumption that patients across the socioeconomic gradient prioritise different aspects of their care, resulting in differing behaviours, preferences, and levels of participation. Patients and doctors can have different perceptions of the communication behaviours which are utilised by the doctor in the interaction (Kenny et al., 2010), however in the context of our findings this disagreement does not necessarily mean dissatisfaction on the part of the patient. Since low SES patients take a more passive approach to information

exchange, they may be satisfied with not being encouraged to ask questions in the consultation. While patients' control over their own healthcare has increased over time (Harrison, 2018), researchers and clinicians should be mindful that not all patients are interested in taking a more active role in their care. The PCI (section 4.9.3.1) may be a useful way of facilitating information exchange within consultations without forcing patients to take a more active role, as the consultant uses the PCI output to guide the consultation and tailor it to the patient's needs.

I found that the SES differences present in my data were only by education and occupation, not area-level deprivation as measured using IMD decile. This suggests that perhaps individual level SES has more influence over the doctor-patient interaction than area-level SES (Chapter 3).

There seemed to be some gender differences within my data. Generally men used their occupation as a frame of reference for the consultation. This could be due to social norms surrounding gender roles and work, or it could be because all of the consultants in my study were male. However my sample size was limited, thus requiring further study. Only two of the women in my sample had high SES occupations and only four women had high levels of education. If I had recruited more high SES women or had a mixture of male and female consultants, my results may have been different.

8.4.4 Limitations

My study has a number of limitations. Firstly, my observation of the consultations may have altered the way in which they were conducted. Both patients and consultants may have acted differently than they usually would have, because they were aware of being observed and recorded. In some consultations references were

made by both patients and consultants to the recording equipment being used, so this is a possibility, although one which many qualitative studies of this nature experience. I could have also used video-recording equipment to collect more data from the consultations themselves, however that would have potentially influenced participants' behaviours even more.

Furthermore, when looking at the SES of my participants I found that in some cases the domains of education and occupation were conflicting, thus some participants were high SES in one domain but low SES in the other domain, as opposed to being high or low SES in both domains. For simplicity I classed participants as either high or low SES, however it is clear that SES exists as a gradient, reflecting a complex interaction between levels of material and social deprivation (Townsend et al., 1988) (Chapter 3). If I had analysed my data using SES as a gradient as opposed to comparing two groups, then my findings may have been richer and more nuanced. Therefore this should be an aim for future research projects in this area.

8.5 Conclusion

In conclusion, this study suggests that low SES patients are more passive in their consultations, have different preferences regarding the consultation, and receive less relational talk from consultants, than high SES patients. However such patients do not seem to want the active involvement or relational talk which high SES patients receive, which contradicts the assumptions which some other researchers hold about this patient group. Furthermore, individual level SES seems to play a larger role in these preferences and behaviours than area-level SES.

Chapter 9: Concluding discussion and conclusions

9.1 Discussion

Previous research (which has been outlined in chapter 4) suggests that patients from low SES backgrounds tend to participate less actively in their consultations, engaging in fewer patient participation behaviours such as raising concerns, rapport building, involvement in decision-making, asking questions, and expression of emotions, preferences and opinions (Verlinde et al., 2012; S. Willems et al., 2005). As described in section 4.6, such behaviours are an important part of patient-centred care (Ronald M Epstein & Street JR, 2007) which has been linked with a number of positive outcomes for patients (section 4.7) (Bertakis & Azari, 2011b; Fors et al., 2016; Jani et al., 2012; N. Mead & Bower, 2002; Pirhonen et al., 2017; M. A. Stewart, 1995).

Therefore if low SES patients engage less in the participation behaviours necessary for patient-centred care to take place, this may partly explain why head and neck cancer patients from lower SES backgrounds experience poorer quality of life (section 3.3.1) (Rylands et al., 2016a, 2016b). But most of the current literature focuses on doctor communication behaviours rather than patient participation behaviours, for example the systematic reviews conducted by Verlinde et al. (2012) and Willems et al. (2005).

This led me to conduct the mapping review for my first study (chapter 5), which aimed to map the literature on socioeconomic variations in patient participation behaviours during consultations with doctors. It summarised the patient participation behaviours studied and the SES variables used in the 49 included studies, as well as various other study characteristics. This is more than twice the amount of studies

which were reviewed by Verlinde et al. (2012), who examined studies on patient behaviours, doctor behaviours, or both.

I found that most of the studies included in my review were conducted in the USA and the most commonly studied condition was cancer. However a large proportion of studies did not specify what condition their participants were diagnosed with (if any) or what setting their study referred to. This is important information which is missing, as setting and condition which the patient is consulting for can influence preferred and experienced participation in the consultation (Deber et al., 2007; Degner & Sloan, 1992; Ronald M Epstein & Street JR, 2007) (Chapter 4).

Only three of the included studies had been conducted in the UK, none of which recruited cancer patients. Furthermore, of the 10 studies which recruited cancer patients only one had been conducted with head and neck cancer patients, which took place in France (Bozec et al., 2016). This suggests that my studies outlined in chapters 6, 7, and 8 address an important gap in the doctor-patient communication literature regarding head and neck cancer consultations in the UK.

The most commonly studied patient participation behaviour in the included studies was involvement in decision-making, while raising concerns and building rapport were relatively neglected in the literature. Previous studies suggest that there are positive outcomes associated with rapport building (Arora, 2003; R. M. Epstein et al., 2010; Hall et al., 1988), for example a systematic review by Beck et al. (2002) found that rapport building was associated with outcomes such as quality of life, health status, satisfaction, trust, adherence, and patient understanding (Beck, Daughtridge, & Sloane, 2002). Duggan and Parrott (2001) looked at the nonverbal component of rapport building in interactions with residents at a teaching clinic in an

American medical school and patients who had a history of chronic illness. They found that rapport building was significantly associated with patients providing information about their emotions, beliefs about their condition, and their experience of illness (Duggan & Parrott, 2001). Therefore I looked at a variety of patient behaviours including rapport building as part of my qualitative study (Chapter 8).

Based on the findings of my mapping review I also looked at raising concerns in my third study (Chapter 7) and my qualitative study (Chapter 8). Raising concerns can be an important part of patient-centred care, as part of the Common Sense Model of Illness.

Epstein and Street's (2007) model of patient-centred care mentions the importance of the Common Sense Model, in that both patients and clinicians will have their own differing illness representations which must be elicited and reconciled in order to achieve a shared understanding of the patient's illness as part of patient-centred communication (Ronald M Epstein & Street JR, 2007).

The Common Sense Model of Illness outlines the process behind help-seeking and adherence to healthcare professionals' advice. It is important that a patient raises concerns with the relevant healthcare professionals if they are experiencing any troubling symptoms or issues, whether they are physical or psychological, however this is not always the case. When an individual experiences somatic sensations, for example headaches, they form a representation of these symptoms which consists of possible causes; these can be illness, stress or environmental factors; the identity of the illness and typical symptoms; typical timeline (whether it is acute, chronic or cyclical); consequences of the illness; and how easily it can be controlled. At the same time emotions such as distress are experienced in response to these symptoms

at varying degrees. This in combination with the representation of the symptoms determines the coping strategy which an individual chooses (Leventhal, Diefenbach, & Leventhal, 1992).

The aim of the coping strategy is to reduce the symptoms, and this can be done by using over the counter medications, raising concerns with a GP or other healthcare professional, changing diet or other lifestyle factors, or various other strategies. The efficacy of the selected coping strategy and various other outcomes are evaluated by the individual, which influences whether they continue to use the strategy or try a different one. Representations and coping strategies selected are influenced by previous experiences with illness as well as socio-cultural factors such as gender norms; this means that they are constantly being changed and updated due to new experiences and information received from a variety of sources. Coping strategy selection is also affected by perceived costs and benefits of the strategy (Leventhal et al., 1992). It is important to note that although the individual believes their selected strategy to be appropriate, it may not be effective or medically recommended. If an individual is concerned that their illness may be life-threatening this can prolong their attempts at self-medication before deciding to consult a healthcare professional (Leventhal et al., 1992).

Therefore according to the Common Sense Model and Epstein and Street's model of patient-centred communication, a clinician has the opportunity to influence an individual's illness representation through patient-centred communication. This can lead to utilisation of more adaptive coping strategies by the patient as well as enhanced help-seeking (or raising of concerns), through factors such as increased trust (Ronald M Epstein & Street JR, 2007). The PCI may be a tool which facilitates patient-centred communication and provides a positive clinical encounter, therefore

improving raising of concerns and coping, and potentially resolving the issue of poor communication of needs and lower quality of life in low SES patients.

I found that the most commonly used measure of SES was education level, with relatively few studies looking at occupation or area-level deprivation, and to a lesser extent income and employment status. Previous research suggests that occupation may be an important indicator of SES, as it reflects social deprivation through lack of participation in certain roles, but can also indirectly affect material deprivation through low income (Galobardes et al., 2006a) (Chapter 3). Therefore I used occupation as one of my SES indicators in my qualitative study (Chapter 8) in order to address this gap in the literature. As mentioned in section 3.2.2.5, there are some limitations to collecting data on participants' occupations, as allocating participants to groups can be difficult depending on the accuracy and clarity of their answers, plus the nature of certain occupations can change over time (Galobardes et al., 2006a). These limitations may partly explain the relative paucity of studies using occupation as a measure of SES. This lack of attention to raising concerns and area-level deprivation was addressed by the study outlined in chapter 6.

This study (chapter 6) was conducted by a research group at Aintree Hospital, however I helped interpret and report the findings in the early stages of my PhD. They aimed to examine whether there was a significant difference in the number and type of Patient Concerns Inventory (PCI) items selected by patients of differing levels of area-level deprivation measured using Indices of Multiple Deprivation (IMD) (section 3.2.1), when used in the context of a head and neck clinic. The PCI is a tool which has been designed to help patients raise concerns during head and neck cancer follow-up consultations (section 4.9.3.1). There were no significant differences in terms of the PCI items selected, however patients from more deprived

areas reported worse quality of life. Based on the literature summarised in section 4.4.1.4 we expected to find that patients from more deprived backgrounds would raise fewer concerns using the PCI. It is possible that this lack of difference in the selection of PCI items may have occurred because the PCI was effective in helping low SES patients raise concerns, however because there was no control group we can't say for certain. The findings could have also been due to our use of only one consultant or the measure of SES which we used. Furthermore, some patients may have raised concerns in the consultation itself without reporting them using the PCI. But we would need to analyse the consultations themselves in order to determine that.

The lead me to my next study (chapter 7) which continued to look at raising concerns and area-level deprivation, but through the analysis of head and neck cancer follow-up consultation recordings. My aim was to investigate the impact of area-level deprivation on patients' raising of concerns in a head and neck cancer clinic. This was a study using data which had already been collected by another research team as part of another study, and I hypothesised that patients from deprived areas would raise fewer concerns. I analysed 110 audiotapes of consultations using Verona Coding Definitions of Emotional Sequences (VRCoDES) (section 4.8.2.2) to quantify patients' raising of concerns, and correlated this with patient area-level deprivation data, measured using IMD deciles. There were no significant differences in terms of the number or type of concerns which patients raised during these consultations. This is in contrast to the finding by Siminoff et al. (2006) that breast cancer patients with more than a high school education were significantly more likely to ask questions and introduce topics into the discussion with their oncologist (Laura A Siminoff et al., 2006). However it is

important to note that these patients were all newly diagnosed, whereas the patients in my study had all completed treatment so this difference in time since diagnosis could have influenced patterns of communication within the consultation.

The lack of significant difference found could have also been because individual-level SES variables may have more influence over doctor-patient communication than area-level SES. Therefore in my qualitative study (Chapter 8) I used a range of individual-level SES variables, in addition to IMD.

My findings could have also been due to only using one consultant or the measure which I used to analyse the consultation. One potential issue with using VRCoDES is that the coding scheme was developed by a team of researchers who are at the higher end of the socioeconomic gradient. Therefore the way in which they themselves might raise concerns or express emotions during a consultation may be very different to how low SES patients do so. Low SES patients may have been raising concerns which simply were not picked up by the coding scheme, however this will be a similar issue for other coding schemes (for example the Roter Interaction Analysis System) as well.

It's important to note that prior to most of the consultations analysed (98 out of 110), patients completed the PCI. Therefore, like in the previous study (chapter 6) it is possible that the PCI was effective in helping patients raise concerns, thus reducing SES differences, however due to the lack of a control group we again can't say for sure. I also found that high SES patients had significantly longer consultations, and when I controlled for consultation length low SES patients raised more concerns. However, given that previous research has found that doctors spend more time building rapport with patients higher up the socioeconomic gradient (Laura A

Siminoff et al., 2006), it seems likely that in my study patients from more deprived areas were quick to express their concerns with little small-talk, while patients from less deprived areas had more rapport building and discussion in their consultations.

As mentioned in section 4.8.2.2, the VRCoDES is focused on patients' concerns and healthcare professional responses to these concerns, which makes it quicker to code with than the Roter Interaction Analysis System (RIAS) which codes all utterances within a consultation. However, one limitation of this measure is that the small-talk and general discussion aspect of the consultations would not have been captured by the VRCoDES. Therefore as part of my qualitative study (Chapter 8) I audiotaped and observed patients' follow-up appointments at head and neck cancer clinics in order to find out more about building rapport and raising concerns, as well as the other patient participation behaviours which were the focus of the mapping review (chapter 5). I also wanted to look at the SES measures of education and occupation, as well as IMD to explore the complexities of the relationship between SES and doctor-patient communication.

This led me to my final study (chapter 8) which aimed to qualitatively analyse observed and recorded head and neck cancer follow-up consultations, as well as in-depth interviews with patients. This was in order to look for any SES differences which might be present in patient participation behaviours and doctor communication behaviours, as well as explore what aspects of SES seemed to be important. I recorded 36 consultations with patients from a range of socioeconomic backgrounds in the clinics of 5 consultants, and conducted interviews with 32 of these patients. Three main themes emerged from the data: 'Relational talk', 'Active or passive participation', and 'Patients' preferences'. I found that patients differed

with regard to these themes based on their education level and occupation, however their IMD decile did not appear to have an influence.

Consultants appeared to interact with patients differently depending on their position on the socioeconomic gradient. The tone of consultations with high SES patients was much warmer, with the consultants driving more social talk and using more humour, possibly as a way of creating power and maintaining solidarity within the consultation (Hay, 2000), whereas with low SES patients consultants were colder and much more formal, providing little space for the patient to speak. This is in line with the literature presented in section 4.3.6.4, for example findings from Siminoff et al. (2006) where oncologists spent less time trying to build rapport with breast cancer patients who had a low level of education (Laura A Siminoff et al., 2006). Interestingly, the study also found that patients with less education spent less time trying to build rapport with the consultant than more educated patients (Laura A Siminoff et al., 2006), as outlined in section 4.4.1.4. This fits with my finding that low SES patients did not want the small-talk which high SES patients had received. Low SES patients seemed to want a consultation which was quick and 'to the point', with little chitchat. This is supported by the finding of study 3 (chapter 7) that low SES patients had significantly shorter consultations. Their consultations might have been shorter because they wanted less rapport building or 'chitchat'.

Furthermore, low SES patients were less active in their consultations, placing the responsibility for information provision on the consultants. They believed that the consultants would provide them with any important information, and did not seek information themselves, unlike higher SES patients. This is expected, based on the literature in section 4.4.1.4. Avis (1994) reported similar findings in their study of patients receiving hernia surgery. Patients reported having a more passive approach

to information, expecting important information to be provided to them. This resulted in unmet information needs, although participants still did not try to seek information from clinic staff (Avis, 1994). However this study did not compare findings by patient SES, merely collecting and briefly reporting the variety of occupations held by the participants.

The beliefs surrounding personal responsibility for information-seeking held by high SES patients, have also been found in studies of both healthcare professionals and patients. Willems et al. (2005) interviewed GPs in Ghent to explore their definitions of poverty and their ideas of low SES patients' attitudes towards healthcare. They found that most of the GPs focused on individual characteristics such as personality, for reasons why low SES patients could not improve their financial status or take a more active role in their healthcare, with most GPs ignoring the role of the broader social and structural context of poverty (S. J. Willems, Swinnen, & De Maeseneer, 2005). Sointu (2017) found similar results when interviewing medical students in the USA, some of whom emphasised individual responsibility in health while ignoring the role of wider factors in health inequalities. This was conveyed to them by experienced and senior clinical staff during their training, and portrayed low SES patients as 'bad' patients if they did not possess the knowledge or resources to comply with doctors' orders (Sointu, 2017). Hoej et al (2017) found that staff at a mental health service for young people also sometimes used this responsibility discourse when talking about their service users, however the authors point out that such discourse might result in further disadvantaging marginalised groups such as low SES patients if they are unable to exercise their individual responsibility in this way (Hoej, Johansen, Olesen, & Arnfred, 2017).

I found that low SES patients defined involvement in decision-making as being informed of whatever decisions the consultant made about their care. This was in contrast to high SES patients who wanted to be involved in the decision-making process themselves. Ekdahl et al (2010) found that the hospitalised elderly patients in their study had a similar definition to the low SES patients in my study. They perceived participation to mean being informed of any medical decisions, without making any decisions themselves (Ekdahl et al., 2010). However the study did not collect any information on the patients' SES, therefore it is difficult to determine whether this perception was due to SES or another variable such as age.

Another finding is that low SES patients display more stoicism, preferring to deal with problems on their own and proudly seeing this as part of their identity. Bolam et al (2004) interviewed 30 individuals across the socioeconomic gradient about their perceptions of class and health. They found that low SES participants denied the role of class in health inequalities, emphasising the role of personal responsibility and presenting themselves as having persisted in the face of adversity, in order to avoid being negatively labelled as a victim (Bolam et al., 2004).

The finding that participants differed by education and occupation, not IMD, suggests that perhaps individual SES variables have a greater influence over doctor-patient communication than area-level SES, therefore the relationship between SES and doctor-patient communication is somewhat more complex than originally thought. It is important to note that in this study only male consultants participated, therefore it is difficult to account for the possible effect of gender concordance (section 4.3.5.1). Furthermore, only a few women in the sample were high SES with regards to either education or occupation, which meant that I could not explore the possible interaction between gender and SES. Another limitation of this study, as

well as the previous studies, is that I focused on dyadic communication, which is communication between two individuals, for example a patient and a consultant. However in some instances patients bring a friend or family member into the consultation with them. Often these individuals also contribute to the discussion within the consultation, which may influence the effect of the patient's SES on communication patterns, especially if they are of a different SES to the patient.

Given my finding that consultants are warmer and more familiar in their interactions with high SES patients, while low SES patients receive a much more formal communication style, one suggestion might be to provide consultants with training on building rapport with low SES patients. However, given that low SES patients seem to want a brief, to the point, consultation with little if any rapport building, such an intervention might be ineffective in reducing SES differences. It may even have the opposite effect, and worsen existing socioeconomic inequalities.

In contrast, I think that the PCI may help to reduce SES differences in patient participation behaviours, as it is a quick and easy way for low SES patients to raise concerns. They simply have to select an item on the PCI and leave the consultant to address it, without having to ask the consultant themselves. A qualitative study conducted by Ozakinci et al. (2018) found that some of their participants stated that they would not have raised concerns regarding their fear of cancer recurrence if they had not used the PCI as part of their head and neck cancer follow-up appointment (Gozde Ozakinci, Swash, Humphris, Rogers, & Hulbert-Williams, 2018). This suggests that the PCI helps patients to raise concerns which they may not have otherwise, possibly in part because it gives patients 'permission' to raise concerns.

Furthermore if low SES patients want to get straight to the point, the PCI does this by streamlining the consultation while ensuring that any concerns are raised and addressed. The PCI is cheaper and easier to implement into clinical practice than, say, training doctors to improve their rapport building, plus it may have more impact on improving quality of life for low SES patients. If concerns are raised, they can be addressed, which may improve a patient's quality of life following completion of cancer treatment.

However, so far there have not been any studies which have examined whether the PCI does indeed affect doctor-patient communication, therefore future research should conduct a randomised controlled trial in which patients are either assigned to the group which uses the PCI or the control group which simply receives routine care. These consultations would then be analysed using a measure of doctor-patient communication, such as the VRCoDES. Ideally both arms of the trial would also have an even spread of high and low SES patients, to examine whether the PCI reduces SES differences in patient participation behaviours.

9.2 Limitations

- For my mapping review (study 1, chapter 5), if I had sufficient time and resources it may have been advantageous to conduct citation chasing and hand-searching as part of my search strategy, however this was not possible at the time and I nonetheless achieved my aim of mapping the patient participation literature. Perhaps it would be useful to conduct a full systematic review on the topic of patient participation and SES in the future.
- With my third study (chapter 7), it would have been useful to collect data on patients' individual-level SES such as occupation and education, to enter into

the analysis. However as this was data which had already been collected as part of another study, it was not possible to obtain this information.

- It may have also been useful to analyse the consultations (study 3, chapter 7) using RIAS instead of VRCoDES, so as to capture the rapport-building elements of the consultations. However given that coding consultations using RIAS takes significantly longer than VRCoDES, I would not have been able to code all of the consultations within the two weeks which I spent at St Andrews University in their secure coding room.
- For my final study (chapter 8), it would have been useful to recruit female consultants as well as male consultants, in order to account for any possible effects of gender concordance. However, given that most of the consultants in both ENT and MFU departments are male (there are only three female consultants across both departments at the time of writing), this would have been difficult to achieve at just one site.
- It may have also been useful to recruit more high SES female patients (final study, chapter 8), however this would have been difficult as the hospital does not keep information regarding patients' education or occupation. I could only obtain this information by asking patients, therefore I could not screen for this prior to approaching patients.
- For my final study (chapter 8), videotaping the consultations would have provided me with more data regarding nonverbal behaviours than simply audiotaping and observing consultations. However this may have made participants feel even more self-conscious and uncomfortable, thus causing them to act differently to how they would normally. Plus videotaping may have resulted in fewer patients agreeing to participate in the study.

- For study 2 IMD data was presented as quartiles (chapter 6), however in studies 3 and 4 (chapters 7 and 8) the IMD data was divided into deciles. Ideally IMD deciles would have been used in all three studies to better compare the findings of each study. However as the anonymous data for study 2 had been collected and analysed prior to the commencement of my PhD, it would have been difficult to reliably and accurately convert from quartiles into deciles.

9.3 Summary of thesis contributions

- These are some of the few patient participation studies which have been conducted with head and neck cancer patients in the UK.
- The findings of this PhD contributes significant knowledge to the field of patient participation in communication and SES, exploring a wide range of SES variables and patient behaviours, while much of the previous research focused on doctor communication behaviours.
- The qualitative study (chapter 8) is the first study to compare use of humour in clinical interactions by patient SES.
- The findings of these studies lend further support to the routine use of the PCI in clinical practice, providing a springboard for randomised controlled trials to investigate its impact on the consultation further.

9.4 Summary of conclusions

- Patients from lower socioeconomic backgrounds prefer not to raise concerns or build rapport in their consultations at the head and neck clinic. They seem to just want a brief and ‘to the point’ consultation.

- Individual level socioeconomic status (SES) variables such as education and occupation, seem to have a greater influence over doctor-patient communication behaviours than area-level SES.
- SES is a complex concept and doesn't have a simple relationship with doctor-patient communication.

9.5 Recommendations for practice

- The Patient Concerns Inventory (PCI) may be effective in reducing SES differences in patients' raising of concerns during head and neck cancer follow-up consultations, as suggested by the findings of studies reported in chapters 6 and 7. Based on the findings of the qualitative study (chapter 8) it seems that low SES patients prefer a streamlined consultation, which the PCI may be able to provide. Therefore routinely using the PCI in head and neck oncology clinics may help to reduce socioeconomic inequalities in doctor-patient communication, as well as quality of life.

9.6 Recommendations for future research

- The suggestion that the PCI may reduce socioeconomic differences in raising of concerns is somewhat limited by the lack of control groups in the studies presented in chapters 6 and 7. Therefore a randomised controlled trial (RCT) is needed, which compares the patterns of communication (particularly with regard to raising concerns) in consultations using the PCI with consultations which do not use the PCI. Both groups would have a spread of patients across the socioeconomic gradient so that SES differences could be tested for, and ideally both male and female consultants would take part in the study.
- The findings of the qualitative study (chapter 8) and the literature on SES (chapter 3) suggest that SES is a complex concept with various measures that

capture different aspects of deprivation. Not all measures of SES have an influence over doctor-patient communication, therefore future research projects should use more than one measure of SES in order to gain a nuanced understanding of the relationships between SES and their variables of interest.

- The studies which I have completed as part of my PhD have all focused on dyadic communication within consultations, however the role of other parties (for example friends or family) present in the appointment may affect patterns of communication. Future research should look beyond the doctor-patient dyad, and also analyse the influence of other individuals participating in the interaction.
- When analysing consultations using coding schemes such as the VRCoDES, large sample sizes are necessary in order to increase the statistical power of the study and aid generalisability of findings. However coding audio recordings can be very time-consuming. Recently researchers have developed computer software which can automatically code consultation audio recordings or transcripts using VRCoDES (Luke Barracliffe, Arandjelovic, & Humphris, 2017; Birkett, Arandjelović, & Humphris, 2017). This may allow researchers to analyse large numbers of consultations at a time, in a much less time-consuming manner. Therefore researchers should consider using this for future research projects.

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Appendices

Appendix 1. Medline (Ovid) electronic search strategy

# ▲	Searches	Results
1	Chronic Disease/	246072
2	(chronic adj3 (diseas* or condition* or medical*)).tw.	244359
3	Patient-Centered Care/	15618
4	((patient* or health*) adj3 (empower* or percept* or perspective* or activat*)).tw.	59435
5	((ongoing or continu*) adj3 care*).tw.	20788
6	or/1-5	537049
7	exp *Educational Status/	7671
8	exp *Socioeconomic Factors/	146986
9	exp *Health Status Disparities/	7604
10	exp *Income/	28082
11	exp *Employment/	41673
12	exp *Social Class/	12148
13	socioeconomic*.mp.	188474
14	disadvantaged.mp.	10832
15	deprived.mp.	25919
16	"low income".mp.	28098
17	"educational status".mp.	49215
18	"occupational status".mp.	2021
19	((poverty or income or educational* or occupation* or "low income" or social) adj2 (analysis or disadvantage* or specific or difference* or factor* or inequalit* or depriv* or inequit* or disparit*)).mp.	37356
20	((occupation* or income* or education* or social) adj3 (grade* or level* or status)).mp.	114411
21	Vulnerable Populations/	8334
22	(vulnerable* adj2 (patient* or populat*)).tw.	10738
23	or/7-22	461469
24	(question* adj4 (ask* or query or queries or enquir*)).tw.	22310
25	(rais* adj4 (concern* or query or queries)).tw.	21046
26	(involv* adj4 decision*).tw.	7691
27	(build* adj4 rapport*).tw.	400
28	(express* adj4 (opinion* or prefer* or emotion*)).tw.	22858
29	Professional-Patient Relations/ or Decision Making/ or "surveys and questionnaires"/ or patient health questionnaire/ or Patient Preference/	489889
30	((ongoin* or continu*) adj3 relationship*).tw.	2063

31	or/24-30	553148
32	6 and 23 and 31	4448
33	(exp Child/ or Adolescent/ or exp Infant/) not exp Adult/	1726772
34	32 not 33	4145
35	Animals/ not Humans/	4394059
36	34 not 35	4144
37	Developing Countries/	69382
38	36 not 37	4119
39	limit 38 to yr="1980 -Current"	4104

Appendix 2. Ethical approval for the qualitative study

NHS
Health Research Authority

North West - Haydock Research Ethics Committee
3rd Floor - Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0207 104 8012

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

27 June 2016

Professor Rebecca Harris
Professor
University of Liverpool
Department of Health Services Research
Block B, Waterhouse Building
1-5 Brownlow Street, Liverpool
L69 3GL

Dear Professor Harris

Study title:	**Influence of the Patient Concerns Inventory in the communication of head and neck cancer patients with healthcare professionals across the socioeconomic gradient**
REC reference:	**16/NW/0474**
Protocol number:	**UoL001221**
IRAS project ID:	**205087**

The Research Ethics Committee reviewed the above application at the meeting held on 14 June 2016. Thank you to Sarah Allan for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Ms Rachel Katzenellenbogen, nrescommittee.northwest-haydock@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Favourable opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

1. Make the following changes to the Participant Information Sheet:
    a. Use the full study title.
    b. Inform participants about their data remaining in the study even if they withdraw.
    c. Change "This will be used to guide a telephone interview which will take place a few weeks after your appointment" to "This will be used to guide a telephone interview which will take place a few days after your appointment."
    d. Provide participants with information about the consultation recordings being kept. This should include:
        a. How long the data will be kept.
        b. How it will be stored.
        c. Who will have access to it.
        d. That it will be used in future research.
2. Make the following changes to the consent form:
    a. Use the full study title.
    b. Remove the third consent point.
    c. Add a consent point for the long term storage of the consultation audio recordings and the use of them in future research.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Summary of discussion at the meeting

Social or scientific value; scientific design and conduct of the study

The Committee was concerned that recording the sessions would alter the behaviour of the participants so that the information gathered would not be valid, as a clinician was likely to make an effort to be nice when observed.

The Committee asked if the knowledge of being recorded would affect the clinicians behaviour, with them possibly being nicer than usual.

The researcher said that there was the potential for behaviour to be influenced by the recording but that this was inevitable in this kind of study.

The Committee discussed this and concluded that as the consultation was primarily a means to develop questions for the interview, a change in behaviour would have less impact than if the consultations themselves were the main part of the study.

The Committee noted that the application was inconsistent about how soon after the consultation the interview would take place and asked for clarification.

> The researcher explained that it had originally been a few weeks but had been changed to a few days.

The Committee agreed this was acceptable but noted that the Participant Information Sheet would need to be corrected.

The Committee asked why the clinician would not be interviewed.

> The researcher explained that it was a pragmatic decision as there was simply not enough time to undertake a second set of interviews.

Recruitment arrangements and access to health information, and fair participant selection

The Committee was unclear how the participants would be chosen to ensure a good spread of socio economic groups.

The Committee asked how many participants would be recruited.

> The researcher said that they were planning to recruit 40 patients although if data saturation was reached earlier then recruitment would be stopped.

The Committee asked if participants would be selected on a first through the door basis.

> The researcher said that would form part of the recruitment, but if there were problems recruiting participants from lower socioeconomic levels then they would work with the clinical trials nurse to identify more potential participants at that level.

Favourable risk benefit ratio; anticipated benefit/risks for research participants (present and future)

The Committee agreed that the researchers had considered and addressed many potential issues, such as coercion and causing participants distress.

Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

The Committee was pleased to note that no identifiable patient data would accessed outside the clinical care team.

The Committee noted a discrepancy as the consent form said data would be destroyed if a participant withdrew but the Participant Information Sheet said that data could only be withdrawn prior to anonymisation.

The Committee asked for an explanation of how data could be destroyed when it was being anonymised.

> The researcher said that data would be identifiable using ID numbers.

The Committee asked if it would be possible to look up someone's ID number and use that to find and destroy the data.

> The researcher said it could be done but they were not planning to keep a list of names and id numbers.

The Committee agreed that there was no reason that the link document could not be securely kept and used to destroy data. However, the Committee agreed that it was acceptable to not do this providing participants were accurately informed that they could not request their data be removed from the study.

The Committee appreciated that participants would be offered a copy of the study publication as this not only served as a thank you for their participation but allowed them to see the results.

The Committee asked how long the recordings of the consultation would be kept.

> The researcher said they would be kept for around five years for other members of the research team to listen to and analyse.

The Committee agreed that this contradicted all the information that participants received regarding recordings. The Committee was not opposed to the recordings being kept but agreed it could only happen if participants were fully informed about it. The Committee stipulated that information about this, including how long the recordings would be kept, who would have access to them and why they would access them, should be included in the Participant Information Sheet and a specific consent point for this added to the consent form.

Informed consent process and the adequacy and completeness of participant information

The Committee noted that the consultants were only being verbally informed about the study and consented. The Committee agreed that as the consultants would simply be recorded doing their normal job that this was acceptable.

The Committee noted that the Participant Information Sheet did not have the full study title on it. The Committee agreed that this was probably because the researchers did not want to offend potential participants but concluded that honesty and transparency required the full study title to be on the information sheet.

The Committee asked the researcher to explain why the full study title had not been put on the Participant Information Sheet or consent form.

> The researcher explained this had been done on the advice of her supervisors, the thought being that mentioning socioeconomic status could affect how participants responded in the interviews. The researcher explained that they did not wish to make participants feel inhibited in expressing their feelings to clinicians or to the researchers.

The Committee understood this but stated that as socioeconomic status was fundamental to the research it was important to include it in participant facing documents in the interests of transparency.

The Committee noted that the Participant Information Sheet should state "the findings will be anonymised" rather than "the results will be anonymised".

The Committee agreed that the potential for distress should be included in the Participant Information Sheet along with information about how it will be addressed.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Confirmation of insurance]	1	05 August 2015
Interview schedules or topic guides for participants [Example initial topic guide]	2	20 May 2016
IRAS Application Form [IRAS_Form_27052016]		27 May 2016
IRAS Checklist XML [Checklist_31052016]		31 May 2016
Letter from funder [Postgraduate research studentship]	1	24 September 2015
Letter from sponsor [UoL sponsor approval]	1	25 May 2016
Participant consent form [Participant consent form]	1	07 April 2016
Participant information sheet (PIS) [Communication of head and neck cancer patients with healthcare professionals]	1	07 April 2016
Referee's report or other scientific critique report [Peer review assessment form]	2	26 April 2016
Research protocol or project proposal [Influence of the Patient Concerns Inventory in the communication of head and neck cancer patients with healthcare professionals across the socioeconomic gradient Protocol]	3	26 May 2016
Summary CV for Chief Investigator (CI) [Curriculum vitae- Rebecca Harris]	1	27 April 2016
Summary CV for student [Curriculum vitae]	1	26 May 2016
Summary CV for supervisor (student research) [Curriculum vitae]	1	01 March 2016

Summary CV for supervisor (student research) [Resume]	1	08 May 2015
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Phase 2 study process]	1	27 May 2016

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

16/NW/0474	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Dr Tim S Sprosen
Chair

E-mail: nrescommittee.northwest-haydock@nhs.net

Enclosures:	*List of names and professions of members who were present at the meeting and those who submitted written comments*
	"After ethical review – guidance for researchers"
Copy to:	*Alex Astor, University of Liverpool* *Ms Michelle Mossa, Aintree University Hospital NHS Foundation Trust*

North West - Haydock Research Ethics Committee

Attendance at Committee meeting on 14 June 2016

Committee Members:

Name	*Profession*	*Present*	*Notes*
Mrs Moyra Ann Baldwin	Retired Senior Lecturer - Oncology	Yes	
Mr Stephen Edgar	Designer	No	
Dr Michael U Eshiett	Consultant Physician in Neurological Rehabilitation	Yes	
Mr Simon Hill	Pharmacist	No	
Dr Ben Johnson	Consultant Psychiatrist	Yes	
Dr Ezzat Kozman	Consultant Gynaecologist	Yes	
Mr Charles Otim	Research Support Officer	No	
Dr Peter Owen	Retired Mathematics Lecturer	Yes	
Dr David Pilling	Consultant Radiologist	Yes	
Miss Anna Sekula	Nurse	No	
Dr Valerie E Siddall	Retired Senior Manager - Pharmaceutical Industry (Alternate Vice-Chair)	Yes	
Dr Tim S Sprosen	REC Chair - Epidemiologist	No	
Dr Zhe Wang	Medical Statistician	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Ms Rachel Katzenellenbogen	REC Manager

Appendix 3. Example topic guide for interview

Introduction

- Researcher's name and University of Liverpool
- Study topic and aims
- Confidentiality and anonymity
- Explain recording, length and nature of discussion, and data storage
- Explain consent issues e.g. may withdraw at any time, don't have to answer any questions they'd prefer not to, need to inform Professor Rogers and head and neck clinical nurse specialist if disclose cause for concern.
- Any questions?
- Obtain verbal consent
- Check if happy to continue
- Start recording

Main questions	**Possible probes**
To start with I would like to learn a bit more about you…	
Tell me about what has happened in your cancer journey up until now	Who else in the family/friends were involved?
Now I would like to ask you a few questions about the appointment which I sat in on	
How were you feeling on that day before the appointment?	Was there anything you were worried about or wanted information about? What were they?
How did you feel about how the appointment went?	How did you feel about the way the doctor spoke to you? Can you tell me a bit more about that?
Questions based on taped consultation: Do you remember when you mentioned your problems with your throat? (mucus) Do you usually see (consultant)? Not much smalltalk in appointment? Quite soon into physical exam? Offer of contra-swallow? Ask about what will happen?	Can you tell me a bit more about that? What was the outcome? What made you raise that issue? How well did you feel the consultant addressed this? How did it impact you?

Not very busy waiting room? Mention upcoming gallbladder scan? Not happy with consultation/outcome?	
How did you get on with the consultant?	Can you tell me a bit more about that? Do you remember what you spoke about? Was there anything you wanted to mention, but didn't?
How do you think you acted during the appointment?	Can you tell me a bit more about that?
I would like to ask you about your experiences with healthcare professionals in general, now	
How generally talk to healthcare professionals?	
Some issues less important than others?	Expressed concerns?
Previous experiences with healthcare professionals?	
General expectations about healthcare professionals and appointments?	
Expectations of degree of involvement in decisions?	
Winding down the interview	
How would you change the consultation?	
Thoughts on the term 'cancer journey'?	If don't like it: Why? What would you prefer instead?
Age leaving formal education Highest qualification Employed currently? Current/former occupation	
Any other points you would like to talk about?	

Ending the interview

- Thankyou for taking part.
- Assurances about confidentiality.
- End recording.

Appendix 4. GCP certificate

NHS
National Institute for Health Research
Clinical Research Network

CERTIFICATE of ACHIEVEMENT

This is to certify that

Sarah Allen

has completed the course

Introduction to Good Clinical Practice eLearning (Secondary Care)

April 14, 2016

Modules completed:

Introduction to Research in the NHS
Good Clinical Practice and Standards in Research
Study Set Up and Responsibilities
The Process of Informed Consent
Data Collection and Documentation
Safety Reporting

This course is worth 4 CPD credits

CPD
The CPD Certification Service

National Institute for Health Research
Clinical Research Network

Appendix 5. Consent form for qualitative study

PARTICIPANT CONSENT FORM

Title: Influence of the Patient Concerns Inventory in the communication of head and neck cancer patients with healthcare professionals across the socioeconomic gradient

Researcher(s): Sarah Allen, Professor Simon Rogers, Professor Rebecca Harris, Dr Steve Brown

Please initial box

- I confirm that I have read and have understood the information sheet dated 19/01/17 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline. Any data collected prior to withdrawal will be included in the study. ☐
- I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications. ☐
- I understand and agree that my participation will be audio recorded and I am aware of and consent to your use of these recordings for analysis in this study. ☐
- I understand and agree that the audiotape of my head and neck review appointment will be stored at the University of Liverpool on a password-protected computer for 5 years so that members of the research team may listen to it in future. ☐
- I understand that my responses will be kept strictly confidential, however if I express something which is a cause for concern the researcher is required to inform Professor Simon Rogers and the Head and Neck Clinical Nurse Specialist so that they can provide any appropriate support or referral for me. ☐
- I understand and agree that once I submit my data it will become anonymised and I will therefore no longer be able to withdraw my data. ☐
- I agree to take part in the above study. ☐
- The information you have submitted will be published as a report; please indicate whether you would like to receive a copy. If yes, please provide details of where to send this report below: ☐

Email: ☐

Postal address: ☐

Participant Name	Date	Signature
Name of Person taking consent	Date	Signature
Researcher	Date	Signature

1 copy to participant; 1 copy to researcher.

Principal Investigator:
Professor Rebecca Harris
Department of Health Services Research
0151 795 5334
harrisrv@liverpool.ac.uk

Student Researcher:
Sarah Allen
Department of Health Services Research
0151 795 5317
sarah.allen@liverpool.ac.uk

Appendix 6. Information sheet for qualitative study

Project title: Influence of the Patient Concerns Inventory in the communication of head and neck cancer patients with healthcare professionals across the socioeconomic gradient

Researcher: Sarah Allen

Supervisors: Professor Rebecca Harris, Professor Simon Rogers & Dr Steve Brown

You are being invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. Please also feel free to discuss this with your friends, relatives and GP if you wish. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Background

Patients diagnosed with head and neck cancer experience a number of serious needs either as a direct result of the cancer or due to treatment, such as difficulty with speech and swallowing, as well as fear of recurrence. These needs can be addressed if the patient informs a healthcare professional, however if they do not the concern can go untreated and potentially result in poorer wellbeing.

This study aims to explore why some people feel more comfortable expressing concerns to a healthcare professional than others, as well as investigating previous experiences with and attitudes towards healthcare professionals.

You have been invited to take part because you have completed your treatment for head and neck cancer and are attending a head and neck oncology review clinic at Aintree hospital. Taking part in this study is voluntary and you are free to withdraw at any time without explaining why.

What will happen if I choose to take part?

If you take part in this study your next appointment at the head and neck oncology review clinic will be observed and audiotaped by the researcher. This will be used to guide an interview which will take place a few days after your appointment. You will have the choice of whether this interview takes place over the phone, at your home or in the Aintree hospital clinical research facility. A convenient time and place for the interview will be arranged if you contact the researcher to express interest in the study. During the interview you will be asked to discuss your appointment, as well as experiences with cancer

and healthcare professionals. This will be audiotaped and analysed by the researcher at a later time.

Potential risks

There is a low risk of experiencing some distress as a result of taking part in the interview because you will be asked to discuss your experiences with cancer outside of your appointment. You are free to end the interview at any time if you feel it is too upsetting. We have also provided the contact details of two cancer support groups on the last page of this information sheet if you feel you need someone to talk to.

Possible benefits

There are no intended benefits of taking part at this time.

What if I am unhappy or there is a problem?

If you are unhappy, or if there is a problem, please let the researcher know by contacting Sarah Allen at sarah.allen@liverpool.ac.uk. If you remain unhappy or have a complaint and you feel you cannot talk to the research team you can contact the Research Governance Officer at ethics@liv.ac.uk. When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), and the researcher involved. Alternatively, you can contact the Patient Advice and Liason service on 0151 529 3287 or complaints@aintree.nhs.uk

Confidentiality

Personal details will be coded and anonymised so that you cannot be identified from the data. All data will be securely stored on a password protected computer or in a locked filing cabinet. Once your data has been anonymised it cannot be destroyed if you decide to withdraw from the study.

Please note that if during the interview you give any information to the researcher which is a cause for concern (e.g. self-harm), they are required to inform Professor Simon Rogers and the Head and Neck Clinical Nurse Specialist so that they can provide any appropriate support or referral for you.

The audiotape of your appointment will be stored for 5 years on a password protected computer at the University of Liverpool so that members of the research team may listen to the tapes in future.

Results

After completion of the study results will be published in an academic journal and the Head and Neck Patient and Carers Research forum website (www.headandneckcancer.co.uk). The findings will be anonymised so that you will not be identifiable from the results.

What will happen if I want to stop taking part?

You are free to withdraw from the study at any time without explanation if you wish. Results up to the period of withdrawal may be used if you wish, otherwise you may request that the data is destroyed and no further use is made of them. Since the results will be anonymised they may only be withdrawn prior to anonymisation.

Who can I contact if I have further questions?

The research team

Sarah Allen:

- sarah.allen@liverpool.ac.uk
- 0151 795 5317

Professor Rebecca Harris:

- harrisrv@liverpool.ac.uk
- 0151 795 5334

Professor Simon Rogers:

- Simonn.rogers@aintree.nhs.uk
- 0151 529 5287

Independent advice on the conduct of research

University of Liverpool Research Governance Officer:

- ethics@liv.ac.uk

Advice and Support

Patient Advice and Liason Service:

- Aintree University Hospital
  Longmoor Lane
  Liverpool
  L9 7AL
- *0151 529 3287*
- *complaints@aintree.nhs.uk*

Sunflowers- supporting people living with cancer:

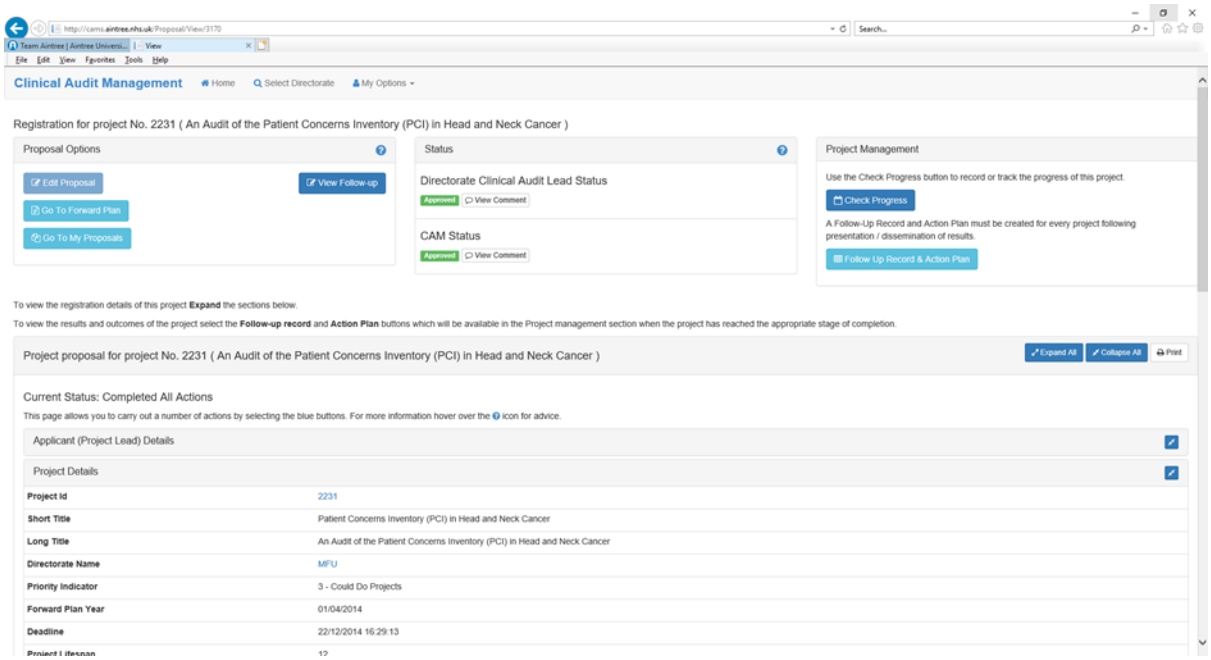
- 21 Aigburth Rd
  Liverpool
  Merseyside
  L17 4JR
- 0151 726 8934

- *www.liverpoolsunflowers.com*
- emma@liverpoolsunflowers.com

Macmillan Support Line:

- Monday – Friday, 9am – 8pm
- 0808 808 00 00

Appendix 7. Ethical approval for Study 2



Appendix 8. Systematic mapping review protocol

Systematic mapping review protocol

Title: Socioeconomic differences in patient participation behaviours in doctor-patient interactions – a systematic mapping review of the literature

Background:

Several systematic reviews have been conducted on SES differences in doctor-patient communication and patient participation with quantitative studies, a recent one having been conducted by Verlinde et al. (2012). This review measured SES using education, income, occupation and social class. The authors found that low SES patients tended to participate less actively in their consultations, by asking fewer questions, being less likely to express their opinions or emotions, expressing a lower preference for shared decision-making, and being less likely to volunteer information unprompted than their high SES counterparts. Furthermore, low SES patients were approached in a more directive manner by clinicians, spending less time building rapport, being less likely to give advice or discuss cancer screening, and being less likely to listen to them than high SES patients (Verlinde, De Laender, De Maesschalck, Deveugele, & Willems, 2012). This was an update of an earlier systematic review on SES differences in doctor-patient communication (Willems, De Maesschalck, Deveugele, Derese, & De Maeseneer, 2005). Differences in patient participation therefore seems to be a key way in which patients from different socioeconomic backgrounds differ.

While there does not seem to be a standard definition of patient participation (Richard, Glaser, & Lussier, 2017), most studies focus on behaviours which are deemed as intrinsic to patient-centred care, such as question asking, raising concerns, and expressing opinions, preferences and emotions (Epstein & Street JR, 2007). This is reflected in the findings of the Verlinde et al. (2012) systematic review described above. For example, Siminoff (2006) examined rapport building, question asking and volunteering information without prompting in a sample of breast cancer patients (Siminoff, Graham, & Gordon, 2006). Street (1992) looked at expression of opinions and emotions with parents of paediatric patients (Street, 1992). The systematic review examined both patient's tendency to participate as well as their desire to participate in clinical consultations. However most of the studies included in the review focused on healthcare professional communication behaviours rather than patient communication behaviours.

Based on these studies, we identify the need to map the existing literature on patient-participation behaviours in doctor-patient interactions. We define patient participation behaviours to consist of question asking, raising concerns, involvement in decision-making, rapport building, and expression of opinions, preferences and emotions.

Since health system reimbursement and provider cultural characteristics have been shown to influence patient participation (Ayonrinde, 2003; Peluso et al., 2018; Slowther, Hundt, Purkis, & Taylor, 2012), we are therefore restricting the review to systems in 'developed' countries as defined by the OECD's Development Assistance

Committee list of Official Development Assistance recipients. This is to facilitate comparison with the results of the qualitative study and the PhD as a whole, which was also undertaken in this context. This is because such countries are low or middle income according to the World Bank, or Least Developed Countries according to the United Nations, and are therefore likely to have a very different healthcare system from the UK, as well as very different socioeconomic inequalities in healthcare.

We will also be excluding studies of screening appointments and emergency admissions because we are interested in the doctor-patient relationships developed as part of ongoing care. Furthermore the scope of the review would be too broad if these studies were included.

Given that prior to 1980 there was much less electronic indexing, we are only including studies published from 1980 onwards.

Review question: What research has been done to explore why does the tendency to and desire for patient participation behaviours in healthcare consultations with doctors vary according to SES and what aspects of SES have been explored?

Aim:

- To map the characteristics of published studies which provide data on the link between patient participation behaviours and socioeconomic status.

Inclusion criteria:

- Studies with data given on patient perspectives on actual and desired question asking, raising concerns, involvement in decision-making, rapport building, or expression of opinions, preferences and emotions.
- SES gradient in the form of education, income, occupation, or other measures
- 1980 onwards
- Adult patients only
- Only studies which focus on doctor-patient interactions
- Written in English language only

Exclusion criteria:

- Healthcare professional perspectives only
- Patients under 18 or parents of patients only
- Adult patient perspectives of childhood experiences
- Countries on the OECDs Development Assistance Committee list of Official Development Assistance recipients
- Patient perspectives about emergency attendances and screening appointments
- Opinion articles
- Systematic reviews

Electronic databases:

- Medline
- CINAHL
- PsychINFO
- Web of Science

Data collection

A reviewer will screen titles and abstracts for selection and remove duplicates, with a second reviewer only screening 1 in 5 titles and abstracts, then the full text of selected studies will be obtained. Two reviewers will then independently screen the full texts for inclusion in the study, and any disagreements will be resolved through discussion with a third reviewer. The second reviewer will only screen 1 in 5 full texts for inclusion. Both reviewers will then extract data from the included studies using the extraction form below, and disagreements will be resolved in the same manner as before. Endnote will be used to manage references throughout screening of titles and abstracts, as well as data extraction.

Data to be extracted	
Title of study	
Authors	
Year published	
Study methods	e.g. questionnaire, qualitative interviews, etc
How SES is measured	
Sample size	
Patient participation behaviours measured	
Patients over 18 years of age?	If no, exclude
Country conducted in	If on OECD DAC ODA list, then exclude
Patient population recruited	e.g. diabetes, breast cancer, HIV, COPD, etc
Associations reported	

Data analysis

Because the purpose of this review is to map the literature in the field of patient participation behaviours, no analysis of the data will be conducted as we are looking to detect patterns in a large body of data.

Appendix 9. Example face to face interview transcript

Patient: 12 **Consultant: 3**

Patient Just want to turn my phone, make sure my phone's off.

INT It's alright.

Patient As soon as we start talking it'll start ringing I guess…

INT Laughs.

Patient Okay.

INT Okay. So to start with I'd like to learn a bit more about you. So erm… could you tell me what has happened in your cancer journey up until now.

Patient Well about 2 ½ years ago now… I think it was 17,16,… 2014 I erm found a small lump in my neck, just under my jaw bone on the left hand side and I'd just had a cold or a flu or something at the time. I wasn't ill, no symptoms or anything except having a cold or the flu. So I thought I just had some swollen glands, so I didn't do anything about it and I just forgot about it completely at the time, because it wasn't doing me any harm, it wasn't that noticeable. Erm… I can't even remember how I actually found it initially like, you know,… just feeling my jaw line and I just noticed something that… it was like a bit swollen…slightly swollen, it wasn't even that visible. So I just left it and did nothing about it. Then in early in 2015 I was shaving one day and the shaver went over this little bump again and I thought, that's still there like. I then started to get slightly worried thinking there's something there that's been there now for a good 4 or 5 months maybe. Erm and I couldn't find anything similar on the other side like, you know. So I thought, there's something not quite right here, but I didn't think automatically about cancer to be honest… I just thought it was a benign lump of some sort. So I thought I'd better go and get it checked out. So I went to the doctor and erm… the GP had a look at it and he said yes there is a growth there, I'm going to have to refer you, but I wouldn't be too worried about it because I think it's a benign growth, probably in your salivary gland, or around your salivary gland. Erm… and that was the Thursday night and by the Tuesday I was in front of Mr (consultant), which worried me a little bit like because, you know, I thought… that happened very quickly. [Laughs] Even if he is telling me like, you know, that it doesn't seem like very much. Erm, but, interestingly when Mr (consultant) first erm checked me out and had

a look, you know down… with the scope down my throat and felt everything, he said "yes there's definitely a growth there, but again, like your GP, I think it's a benign growth". He said "I'm almost 90% sure that it's a benign growth, and it probably isn't anything to do with your salivary gland, it's probably around your lymph node. It's probably growing around the lymph node like, yes." He said "It will have to come out because even if it is benign it could turn cancerous in the future." So I felt a bit relieved. Erm… and then he said we'll have to get it investigated obviously like yes. So he sent me for scans and biopsies and I went back 2 weeks later to be told it was a cancerous lymph node. So that was a bit of a shock.

INT Yes.

Patient And I remember he even said, Mr (consultant), he said "I told you when you were last here that it was probably 90% benign", he said, "now you are going to be shocked when I tell you this, because I was shocked, but it has come back as cancerous", and I went "alright, where do we go from here then?" [Laughs] Erm, so he said "well I told you it will have to come out, so it does to come out", he said, "there's good and bad news here," he said, "that is the good news is that it doesn't seem to me that it has gone any further than the lymph node, the bad news is that is a secondary not a primary. So that means there is a tumour somewhere that we have to find because it is not obvious when we investigate", like you know what I mean, "that there's a tumour anywhere, but the type of cancerous cell that it is, squama cell carcinoma," he said "that type of cancer cell comes from soft [unclear] tissues, so it's most likely to have come from your tonsils or your mouth or your throat – that region where most of these cells predominate." So erm… he then… this was the worst part of it… because he said "eventually we will have to take that out but first before we take that out, that lymph node, we have to go and investigate where this primary is, and that means doing lots of biopsies in your throat, your tongue and erm taking your tonsils out." And that was the worst part of every bit of feedback that I've had. The pain was horrendous, this was nothing, you can see my scar there, that was nothing compared to what they were doing in there. Erm, it was awful like, yes. And the funny thing was he didn't take both tonsils out the first time. He only took one out because he said "your tumour… your cancer lymph node is on your left side so it is most likely that it has come from that side."

INT Right.

Patient "So your mouth or your tonsils, so we won't…. both tonsils look okay to look at but that doesn't mean there's not a tumour somewhere." So he said, "We'll just take one

out first of all and do some biopsies, because we don't take healthy tissue out unless we have to." So he took that out and honestly it was horrendous, the pain for days. He did tell me, he said "for the first 4 days you will be okay and then in 4 days to 8 days you are going to be in a lot of pain" and he was almost exactly right, even though they gave me quite strong pain killers and everything, it was very painful. I then went back to find out they didn't find anything in my tonsil or any of the biopsies they'd done. He said "sadly (patient), you are going to have to come in again and get the other side done. It's not really what we want to do but it could well be in the other side. It's unlikely but I don't know, there's a small chance that it has skipped from that side of your… your… face," do you know what I mean, "to your head to the other side." So I went back in again and had the other tonsil and more biopsies and part of the bottom of my tongue taken away and all that… it was horrible. They didn't find anything there either. So to this day they haven't actually found my tumour. So erm… I didn't realise this at the time, but he said "there is two reasons why your tumour might not be there. One could be erm…. he said it is unlikely to be… well he did scans of my whole body scans and they didn't find tumours anywhere else. He said "it's unlikely to be anywhere else anyway because the type of cell that we found to be is almost 99% sure to have come from inside your mouth, throat, somewhere like that." Erm, he said "right, there's two reasons why it might be there, right… three reasons actually… so the first reason is that radiotherapy in patients can get rid of the tumour before we've ever find it, but you haven't had radiotherapy so that's not the reason; secondly, your body could have gotten rid of the tumour…" now I didn't think that your body could get rid of like tumours that have already spread like, do you know what I mean, to a lymph node right… but he said "yes, your body's defence could have gotten rid of that tumour because it would have been really small. It had to be small because we can't find it. So it's microscopic" and I didn't realise that microscopic tumours could actually spread.

INT **Yes.**

Patient But they can do obviously, like. So… I'll be worrying you telling you all these stories won't I. So… and he said "the third one is, reason is, that it's still there and we haven't found it." And to this day it could still be there. That's why now I go there every three months and he checks around when I see him, because he's looking for this tumour, that's what he's looking for, right. But the longer I go on and the longer they don't find it… the more likely that it's the second one… that my body has gotten rid of it, the tumour like, yes?

INT Yes, yes.

Patient And hopefully, touch wood, that's the case because it's gone then, right?

INT Yes.

Patient So erm… I am up and, as you can see, I am up and normal like, they are not seeing anything or finding anything. My understanding is that by two years now, it's just over two years… even a microscopic tumour would have grown and it would have been noticeable by now. So it is becoming more and more likely that it's gone. So in the first year so they did various scans to start off with and then at the end of the first year they did follow up scans as well and everything was clear like, yes. So I haven't had any scans for the last year, like you know what I mean, and they may well do another one at some stage, like, you know just to check, maybe at the end of the third year. But I am fit and healthy and everything is going well now. I've never had any symptoms… I've always felt healthy that's the funny thing you know. You can have cancer and feel really, really good. So then they took me in for a third operation to take the lymph node out and that was… that was quite a serious operation, like. I was in theatre for about 4 ½ hours or something. I bled a lot as well, like you know, so there was a problem with bleeding. I didn't know at the time obviously because I was out, you know what I mean, but they had a problem stopping the bleeding. So it as longer than they expected. But anyway, they took it out and what he was trying to do was to also be very careful in the operation, and he is a fantastic surgeon, and people have told me he's one of the top head and neck cancer surgeons in Europe like, yes, Mr (consultant). So I'm very lucky I've got one of the top guys, but I think that unit is one of the top units for head and neck cancer in Europe as well. That's a regional unit like you know? So it's used by people all over the North West and North Wales.

INT I think they get Isle of Man patients as well.

Patient Yes, Isle of Man as well. So it's like a specialist unit like yes? So erm… so what he was trying… he was careful in the operation by taking out that lymph node that he knew had cancer in it. He said there may have been another scan showing that there was possibly a second lymph node with cancer in it. So what they wanted to do was take those lymph nodes and all the lymph nodes around there out carefully so that they could check on further examination whether the cancer had gone any further than those lymph nodes.

INT Yes.

Patient Now the bad news would have been that if they'd gone into other lymph nodes, like you know what I mean, and maybe spread somewhere else like? But the good news when I went back was that it was only one lymph node affected and not two at all, and he said, he said to me after the operation, he said "the operation's been very successful, we've managed to get 31 lymph nodes that he took out of my neck there" and he said, "they've all been taken out intact", because they didn't want to, you know, damage them in any way because then that wouldn't have proven whether the cancer had left that node or not, so they wanted to take them out totally intact. He said they've all, so far as we are aware, been taken out totally intact. So that will determine whether the cancer has stayed within the lymph nodes or gone anywhere else. So when I went back for the information about the… about the examination of the lymph nodes there was really good news, because the good news was that only one lymph node had cancer in it and it hadn't gone beyond that lymph node. He could tell virtually 100% that the lymph node that they took out was totally intact, it was also encapsulated, that was the word he used, encapsulated lymph node, which means that it hasn't gone any further. So I was really lucky. So before that they had me down to have 6 weeks of radio therapy on my head and neck and because of that outcome he decided not to do the radio therapy, for a couple of reasons, because he said "well we don't know where the tumour was so we wouldn't even know where we would be directing, you know, the radio therapy, so we'd just be doing it blind. " Something else I learned then as well is that you can only have radio therapy on your head and neck region once.

INT Oh

Patient If they get it wrong and it comes back after your first dose of radiotherapy you are knackered because …. chemotherapy cannot be used without radiotherapy in head and neck cancers…

INT Yes.

Patient So it's one of the cancers where chemotherapy is no good on it's own, it has to be used in conjunction with radiotherapy. So if you do radiotherapy on it's own and then the tumour comes back then there's no other option, like yes?

INT Yes.

Patient Because it's just too damaging to your head and face like, you know, radio therapy to have it more than once like. So he said, "we also know that the lymph node is intact so we are almost 100% sure that the cancer hasn't gone anywhere else. So the best thing for us to do is to just keep an eye on you, see you every couple of months" I think it was every 2 months in the first year and it's now 3 months. He said, "see you on a regular basis and if the worst happens and we do locate the tumour well then we have still got the radio therapy now as an option". Then he can use it properly at the site of the tumour, right? So now I haven't needed any of that…

INT That's good.

Patient … all those tests that he's been doing, sticking the camera down and looking around the back and all the rest of it like that and he's not seeing anything like, it's just the same as it was, do you know what I mean, he just has a look there. So… as I say it's over 2 years now and I won't be clear until 5 years, you know, 5 years… but it's looking good that I have been [unclear 13:59]. So I have had some input into these things as well because I said to him, "have you any idea what caused this cancer?" I used to be a smoker but not for over 20 odd years. So the chance of smoking is fairly unlikely, yes? Erm… I'm not a big drinker, I drink, but I'm not a big drinker. So, alcohol is not an issue like, you know with head and neck cancers. So I said "what about HPV papillomavirus?" He said, "it could be, yes, it could be" and the prognosis for that is really good like, of all the head and neck cancers HPV is like the best, and I said could we not try and find out if I have HPV and he said well we didn't do any tests at the time like, you know, to see if there was HPV, because when we didn't try the tumour we usually look on the tumour but we didn't have a tumour. I said could you not look on the lymph node like, if there was presence of HPV, you know, type 1 or 2, which is the bad ones, would that not indicate that is the likelihood and he said, "yes, that's possibly something we could do." So I was directing my own investigations here like that, and he said, "what do you think we should do?" and I said "well could you find out if they've still got that tissue?" He said "they probably will have likely, I think they keep it for about a year. So let me look into it." The next time I went back he said "Yes they've located the tissue and they are going to do the tests on it." The next time I went back the results were that it was HPV. So they are almost 100% sure that HPV has probably caused it, which for me was good news because that's the one with the best prognosis like, you know? So long term… … and then… because I worked in the medical world, and I worked in the [unclear 15:34] industry as well for 30 years, right, and I have a fair knowledge about this sort of stuff, like yes?

INT Yes.

Patient I said to him, “is there any chance I could have the vaccine do you think?” Now the vaccine is only currently designed for women, you know, in young girls, and usually before they become sexually active, like, before they get HPV, yes? And he said, “it’s, if you’ve already been exposed to the virus, it’s unlikely to do any good.” So I went away and did research on it, like yes,… he was getting a bit fed up with me, I was coming back with these clinical papers and things… I said, “Mr (consultant), I’ve been doing some research myself and I’ve found some clinical data here like, you know, to suggest that this vaccine might work even if you’ve been exposed because it produces such a good immunological response, it can actually clear the virus.” He said, “I am aware of that”, but he said, “the data is not brilliant, like, you know, I know you’ve got loads of papers and I’ve probably seen some of them”. He said, “actually we were going to do a trial here, looking to that but it got turned down on some grounds”. He said, “the thing is, it wouldn’t do you any harm to have the vaccine and it may well, we’d never know, but it may well clear the virus from your body. There is anecdotal evidence to say that people have taken this vaccine and it has cleared the virus.” Erm… he said, “the only problem is it’s not licensed for people who have been exposed to the virus so erm… you’d have to pay for it and you’d have to get a private prescription and I will support you if you want to do that.” So he said, “I tell you what I’ll do first of all…” this is why this guy is really good, he really listens to you and that, you know what I mean. Erm… he said, “what I’ll do is I’ll get in touch with your GP surgery and tell them that I think you should have this vaccine.” He said, “the chances of the GP saying yes, are pretty, are virtually nil. I’ve done this loads of times and I’ve never had one surgery that’s agreed to fund it, because it’s not licensed and it’s about £400 for the vaccine.” I was prepared to pay that to be honest, I was prepared to pay that. He said, “It would be easier for them if it comes to it to get a private prescription and for you to pay for it, it’s easier for them to do that than for us here”, for whatever reason, it was more complicated in the hospital to do that. So anyway, he wrote a letter to them and about a week later the practice manager got in touch with me and said, “we’ve had a discussion, a surgery meeting about your situation and the surgery has agreed to fund the vaccine for you.” Which was a first I think, even he couldn’t believe it. He said, “it was worth a try but I didn’t believe it would happen.” So they purchased the vaccine and I had… there’s not many people who’ve had this… I am pretty unique in having that vaccine after being exposed to the virus and proving that that virus probably caused my cancer. So hopefully, touch wood as well, that that has got rid of that virus from my body and there is less likelihood of it

happening again in the future. The vaccine didn't cause me any problems or anything, or any side effects or anything you know, so…

INT **That's good.**

Patient … now the situation is that erm… I go to see him say every 3 months and he goes through those investigations and you see like the other night and hopefully… they will be like that for 5 years and he'll say goodbye. So that's my little story like, and I feel great and healthy. I feel more healthy now than I did before I was diagnosed I think. I think that's because I am retired from work like, probably got something to do with it. [laughs]

INT **So back to the appointment on Wednesday… erm… how were you feeling on that day? Before you went in for the appointment?**

Patient Always a little bit apprehensive. It doesn't… I don't worry about it honestly like, you know, a lot of people get cancer… it comes out and my wife had breast cancer like 20 years ago, 19 years ago and she didn't take it very well at all and still panics a lot about it. The big C word like to people is pretty scary. Probably because I was quite knowledgeable of the medical world and working in it for many years I was able to deal with it pretty well. So I've never been terrified like in any way, shape or form, you know what I mean like, but when I go to an appointment, yes, you are always a little bit apprehensive, because even though, like the other night, I know I am well and I have no symptoms and I keep checking myself, like, just to make sure I don't see any unusual growths or have sore throats that there is no reason for, like, you know what I mean?

INT **Yeah**

Patient So erm… part of the agreement that we have is that I look after my own health and if anything goes on I get in touch with them, you know what I mean. Anything that I'm not sure about. So I went there the other night feeling pretty healthy and unlikely he's going to find anything, but you never know, you are always a bit apprehensive. Once they stick a camera down like, you know, into the back of your throat, you know what I mean, you just never know what they are going to find? So it's always nice when he says at the end, yes everything's fine, yes. You know what I mean? You see my reaction like, you know, thank God for that. So…

INT **Reassuring.**

Patient Of course it's reassuring and he's a very reassuring person. I mean he's… a fantastic guy yes. That department has been brilliant, you know. Anybody whose got negative issues about the NHS and I am sure there's lots of them, you know what I mean, having worked in it myself I know there is, but erm… I don't have any personal issues about the treatment I've had at Fazackerley has been fantastic. Really fantastic. Maybe that's because cancer services in this city are really, really good. This city for cancer is one of the best places in the UK to be, like. They are very advanced, there is a lot of funding that goes into cancer services here. It attracts the top specialists like and the top cancer teams, so we are very lucky, so I feel very fortunate.

INT Okay. So was there anything that you were worried about or wanted information about on Wednesday at all from your appointment?

Patient Not really, not at the moment, you know, I am going along, like I said before, just to get reassured that everything is okay and everything is going in the right direction. Erm… if I had some symptoms or something wasn't quite right or I was getting sort of maybe sore throats that couldn't be explained like, you would want more answers about that. Erm… but on that particular interview there wasn't anything, I think I just wanted him to double check and tell me that everything was okay, yes?

INT Yes.

Patient But in previous ones like and I've already pertained to this, you know what I mean, when I have had more information, or actually offered my own information, he's been absolutely brilliant, really understanding, really wanting to listen and really willing to like, you know what I mean, help me like you know, with every query that I've made like? So maybe that's partly because I'm pretty knowledgeable about the medical field and can speak to him on a reasonable level, so maybe he gives me a bit more time, I don't know. But he does seem a particularly nice guy, I think, just by the nature of who he is and the work he puts in and the hours that he works like, you know, he doesn't do private work, you can tell that he… actually the whole department doesn't do private work, which is quite unusual. Actually the funny thing was when I first went there from the GP I was still working in the pharmaceutical industry and had private health insurance. So I didn't think I was going to get seen that quickly in the NHS so I asked him could he refer me privately like, assuming that they all did private work, or somebody in the department. He said they don't do private work here, but if you want to go specifically private I can refer you to people that do private. But he said, and it was brilliant what he said, he said "but I will just leave you with this - if you want me to refer you I will do, but I am just going to tell you we are a specialist unit here,

all the surgeons and consultants working here are specialists in their field, you won't get anybody better anywhere else." So I said, "forget about the private let's carry on!" Thank God I did by the way. But that says a lot about them as well like you know, I mean they are giving their time to the NHS like and they've got time for their patients like, you know what I mean. So, a fantastic unit and even all the other staff, the support staff are really nice there and really helpful. You can feel at ease, like you know.

INT So do you feel like you get enough information from Mr (consultant)?

Patient Very much so, yes. Yes… and as I said before, if I don't get all the information, I request it when I meet him and even offer my own information as well. Erm… I will tell you a little story as well like, you know what I mean, which I gave him information that he didn't know about right? I've actually got another condition as well that I was diagnosed with about 10 years ago called thrombocythemia, which means my bone marrow makes too many platelets. Now that in itself isn't a very big issue, particularly in the early part, you know when you are younger, but as you get older, what having too many platelets does is causes, it can… the platelets clot blood like yes?

INT Yes.

Patient But if there are too many platelets blood, as you get older it can cause clots and the clots can lead to strokes which can kill you like, you know? So it can become more serious in later life if it wasn't treated. This was just picked up on a routine blood examine like with my GP. It was like a yearly MOT when they take bloods and all and they just noticed that my platelets were higher – they took blood on three different occasions and it was sort of higher than it should be. So they referred me again and they discovered I had this condition. It's called essential thrombocythemia. So I was put on a drug to treat this and this drug is a bone marrow suppressive right? So it kills the cells that make platelets in your bone marrow yes? But it also kills other cells like white cells and red cells as well and so in the early days of getting the drug you have to be monitored very carefully like because you don't want to have low red and white cells counts and things like that. So eventually you get the dose right that keeps all the cells in check. So for 7 years I just take this drug on a daily basis and it controls my platelets. No side effects, no problems. But I was thinking one day, because I knew a bit about this drug because it used to be used to treat HIV as well and I worked in the HIV arena, so I knew the drug it's called Hydroxyurea or Hydroxycarbamide it's got two different… and I knew of the drug. It was quite ironic while working in the HIV field I was put on a drug like that was used to treat HIV like, for a totally different

condition like, yes? But it is a bone marrow suppressor. So I was thinking, if this is a bone marrow suppressor drug and it kills cells and I have been taking this for many years, is there a chance that this drug could have killed the cancer cells which was why they couldn't find my tumour?

INT Oh right.

Patient So I went on the internet and I went searching and to my shock and surprise I discovered that this drug was licensed in America for the treatment of head and neck cancers.

INT Really.

Patient I said I can't believe this. So I… I printed off all these papers again, this is the second time I went in with loads of papers… and I said to Mr (consultant) about this drug. I had already told him I was on this drug and he didn't actually know much about that drug actually. I said, "did you know that drug has been used to treat head and neck cancers." He said, "No. Where did you get that information?" I said, "well I've got it all here printed off for you!" And there was an oncologist in the, in the clinic at the time, an Indian chap, I don't know his name, with glasses?

INT Dr (oncologist)?

Patient That's him, yes. He was in there at the time, yes. So he looked at the papers and went "I don't know anything about this" and he looked at Dr (oncologist) and he said "do you know anything about this" and he said "I don't know a lot about it but I had heard, I know the drug isn't licensed anywhere else but America, it's not licensed in Europe or Great Britain or anywhere like that." So I said "do you think that drug could have maybe got rid of the tumour that you were looking for, that's not there?" He said," oh you never know it might have done." [laughs] So I had given him information that he didn't know.

INT Yes.

Patient So that's a fourth reason, you know what I mean, that I told you about before. That potentially, that drug that I had been taking for something totally different could… potentially have gotten rid of that tumour when it was still there very small, yes? So the question would have been then well why did it not get rid of the cancer in the lymph node, but the dose I was taking may not have been strong enough to get inside an encapsulated lymph node like. But it may have been effective enough to get into

soft tissue like the tongue, somewhere where the original tumour was, yes? So it has been a two-way exercise. So I have taught him a bit and he's taught me quite a lot. [laughs]

INT **That's quite unusual for a patient.**

Patient It's very unusual. He has told me that I am quite unique like as a patient, you know what I mean with the amount of information that I bring in. But that is because I have worked in that world, you know what I mean, so I have got a lot of knowledge about drugs and conditions because I have spent my life with it. So erm… so I think every time I come along he's wondering what I am going to bring with me the next time. I am just quite happy for him to tell me know that everything's okay like, you know?

INT **Yeah. And on Wednesday you had a bit of small talk with him as well in the appointment, talking about fishing.**

Patient Yes, yes, well that's what I like about him as well, he's very easy going with his patients, certainly easy going with me, so I assume he is with all of his patients. I mean, he initially asked me what I was planning to do when I retired from my job with the pharmaceutical industry which was last year and I said "I am going to do a lot of fishing, I've got a caravan down in Wales and I spend a lot of time down there". So he usually checks up where I've been fishing and what I've been doing because he used to do a bit of fishing himself like, so he's got some personal interest I guess. Erm yes he's the kind of doctor who's interested in you, it's not just all about you know what I mean, getting you in and out as quickly as possible. I am sure that's in the back of his mind, he doesn't want you in there for too long, but he also has a more personal relationship with you, which is nice and I think patients like that, don't they, do you know what I mean? They just don't want to feel just like a body that's gone in there to be examined, like you know what I mean, and then leave like. It's that personal thing, touch, that's so important because it makes you feel much… … if he's nice to me and the staff are nice to me and I go there and am told that either I've got something wrong or everything's alright, I will feel better about it either way, you know what I mean, I will feel a buzz like. When I left there the other night I felt really good. I felt really good that he'd told me that everything was still okay and I felt really good because they were really nice to me, you know what I mean, and treated me like with a bit of respect, and know my name when I go in. You know… that's important, if you've been seeing someone for 2 years and they forget your name… I know they see loads of patients and like, but if they remember your name, you know, you feel special like in some ways, you know?

INT Yes.

Patient That you've struck some kind of chord with that person, you know what I mean? So I think we've got a very good relationship.

INT That's good. Erm… so… Mr (consultant) mentioned something about a nasal spray in the appointment?

Patient Yes, so… I do suffer from like… erm… sort of like a rhinosinusitis but I get it all the time so it's not just when pollen comes out like and when I got my tonsils out it got worse again. So I get a lot of blockages and mucus at the back of my nasal passage and particularly in the morning when I get up it's quite severe. Annoying my wife, you know what I mean, she was shouting at me all the time, I was making all sorts of weird noises. So I said to him, that was just the last time I seen him, like I said, erm… is there anything you could give me for this, do you know what I mean, so he recommended this nasal spray. So I said, "could you do me a favour, could you, when you write the letter…" when he writes the letter, every time he seems me he writes letters to my GP just to do an update and he copies me in as well. He did ask me if I wanted to be copied in. So I didn't ask that. I think the first few letters he didn't and then he said "do you want to be copied in to these letters as well" and I said, "I'd love to yes." So I said "when you write the letter after the last appointment to my GP will you mention in there like that you are recommending that I have this nasal spray for… it's called perennial rhinitis, so seasonal rhinitis is like you know what people get when there's a lot of hay fever, perennial rhinitis is caused by allergies all the year round for whatever reason, it could be pollen, it could be animals, it could be… we've got a cat at home so that might be affecting me, I don't know. Erm… I said "could you just mention in that letter" because it saves me going into the GP because they won't prescribe drugs in the hospital now. You have to go to your GP to get them and that means I would have to make an appointment and then wait etc. I said "just write it in the letter that you are recommending the nasal spray and then they'll just give it to me". So when the letter came through to me I realised that the surgery would have the letter so I phoned them up the day afterwards and said "you should have had a letter from…" this was really efficient this, I was really shocked, I said "you should have had a letter from Mr (consultant) about my recent appointment and he's recommended a nasal spray…" and the receptionist went away and she came back and said "yes, there is a prescription here waiting for you!" They'd actually made a prescription out right away, you know, from having the letter which I thought was really efficient like, I couldn't believe it. So I went and just picked it up and I've been taking

that ever since like, you know. That's just to help alleviate the nasal…. blockage all the time. It's not 100% but it's better than it was like.

INT Great

Patient Definitely.

INT And those letters sort of help you navigate the healthcare system.

Patient Yes, exactly, yes. So… well I knew, because I have a knowledge of the healthcare system as well I knew that if he got it in a letter I wouldn't have to see a GP then, so I would be wasting the GPs time for no good reason, the consultant's recommended it, he's not gonna argue with that is he, you know what I mean. It's a cheap nasal spray it's not like a major cost. So… but I went to the GP… when I first joined the pharmaceutical industry for the first 8 or 9 years I went to see GPs, calling GPs and I got to know GPs very well. Then for the next 20 years nearly I worked with hospital consultants like that. So my job meant that I had to have a good relationship with hospital consultants so that's probably why I am fairly confident with it. Confident and pretty assured with them do you know what I mean?

INT Yes.

Patient I know a lot of patients going in they are probably quite nervous when they go to see a consultant like, you know what I mean, or any doctor, not just because of the illness but because of they see them as somebody quite powerful and very professional and very different. But having worked in that environment over the years I can converse with them much easier. I know the system I know how the system works and make it easier for myself and them as well.

INT Erm.

Patient Your intrigued by all this now aren't you? [laughs] So if you've got a little bit of knowledge like, you know what I mean, you can actually make things happen much better than if you don't. So I probably made a lot of things happen for me, you know, in a nice way… not in a demanding way, because of my knowledge of that environment and knowledge of drugs and diseases and like. I lot of patients would have that.

INT That's really useful. Erm… is it… do you usually see Mr (consultant) at all of your appointments?

Patient Usually but not always. A few times I've seen like senior registrars

INT Okay.

Patient And all of them have been really nice as well, you know… and very helpful and yes. I a haven't got a negative word to say about anything or anybody I've met in the unit to be honest.

INT Do you prefer to see Mr (consultant) or are you not really bothered?

Patient If I've got something to talk to Mr (consultant) about, like the time I was bringing in the clinical papers and things like that. In fact the night I brought in the clinical papers about that drug I was telling you I was taking I may have… I wasn't actually seeing him that night, I was actually seeing one of the registrars. So I explained this to the registrar and he was like…. "pardon I don't know what you are talking about." I said, "could you just mention it to Mr (consultant) because I'd like to see him" and he came in and he listened to what I had to say and he said "okay wait I will see you at the end." So he sort of changed his plans then to see me, because I think he was intrigued by what I was talking about. So erm… so that's it, they can be quite flexible as well I guess. But no… like the other night, if he hadn't been the one to see me and one of the registrars seen me and I was okay and there wasn't anything in particular I wanted to ask him the other night, erm… I'd be quite happy to see the registrar, because I know the registrars, you know the senior registrars are just a level below consultant, so they know what they are doing, you know what I mean. So I trust them all I guess. Now if they wanted some like junior doctor to see me like and do some investigations I wouldn't be so happy about that like.

INT Yes.

Patient But when you get a senior registrar you know they are only a short way from being a consultant, like you know?.

INT So a bit more experienced.

Patient They are experienced people and they are surgeons as well, they do the surgery as well like.

INT Erm… in the waiting room, it wasn't very busy was it on Wednesday? Is that usually the case when you come for your appointments?

Patient Usually the case for me because I usually have later appointments.

INT Alright.

Patient So because I have later appointments there doesn't tend to be as many people around. Saying that I was very unusual the other night to get in so quick. I am normally waiting at least an hour to get in. That was definitely a record, she must have done something for me to see him. Maybe wanted to be let off early like. But that's because he is so busy and he has such large clinics. I mean, we obviously only see one patient and it takes quite a long time who may be diagnosed with maybe terminal cancer or something well that's going to take a lot longer like, you know. He's probably got a lot of serious patients, you know. So them clinics can run on much longer like than they should do. Because there are nights when you can be there until 9:00 o'clock some nights, it's just ridiculous. I mean after coming in doing… he comes in around 7:00 in the morning and then he's doing surgery doing the day, like and clinics, I don't know how he does that, don't know he does it. I know they are well paid like, you know what I mean, but… at the end of the day they are taking on a lot. I don't know how when you get older how you can do that job. He's still relatively young like and fit like, but there are surgeons in their sixties, you know what I mean, I don't know how they do it. It's tough like, and just physically demanding, mentally demanding. Imagine doing quite serious surgery being with serious ill people during the day. But there have been times when I have come in and it has been full in there yes. Erm… but generally it's not too bad, because I generally try to get one after 6:00 o'clock.

INT Okay, so you usually request one.

Patient I request that I get that time, yes, yes. At the end of the appointment I'll go out and have a pint. Interestingly, I got home after that appointment and my wife was putting away the print off for the appointment and she said "whose (name)?" "I said, "what are you talking about?" She said, "This appointment you've given me is for (name)." And I looked at it, because I hadn't looked at it and there was a guy in there earlier on, he'd been called before I was called, an old guy and he was called (name) so… … this guy was like about 80 years of age as well… but it had my time on the day I had agreed on, but all his details and when the secretary at the end went to give me the form his name must have just popped us as (last name) cause it was already in there, I don't know. So when I phoned back there to try and sort it out they said, what's this guy's details, can you give them to us, and so they checked, because they had me down as an appointment next year some time, and they checked his details and they checked his appointment was the one that I was supposed to have, like on

the system. So they had got them the wrong way round. So thank God I did something about it. [laughs] I don't… even when I phoned up I don't know how she made that mistake, you know what I mean, she said my apologies, and sorted it out. She'd obviously had a long day like, yes. [laughs]

INT **Yes.**

Patient Poor (name) would have got a scare if he'd been told like, you know, he thought he was coming back next year and then someone got in touch to say you are coming back in September like? What!! And then you find out it was a guy called (patient)… [laughs] So anyway, they are sorting it out. Usually they get it right.

INT **So earlier, you mentioned that you were quite involved in sort of decisions after your treatment with the HPV vaccine and bringing in clinical papers and things like that… erm… how involved were you when it came to deciding your initial treatment?**

Patient Very much so. Erm… they took me down, sat me down and explained everything that was going to happen and erm… you know, the positives, the negatives, the potential serious outcomes, like, you know of any operation. So I was very clear about everything, you know what I mean, about what was going to happen, for the positive and potentially the negative. Then I had to sign a consent form to like agree to everything. So he was very, very clear about everything, you know so. I don't think there was anything that… if there was I would have asked questions about it anyway like and get him to answer them. But they were very open. I was very impressed with that side of things. He did sit down and go through everything that was going to happen. Not just during the operation but actually the outcomes at the end, you know what I mean – like the level of pain you were likely to…. And I told you before, he said the first four days things won't be too bad when we take your tonsils out, and the biopsies in the mouth, but then from the 4th day onwards and for 4-5 days you are going to be in a lot of pain. So he told me at the very initial stages like, you know what I mean, that those were things to look out for. He made me quite aware of everything that I am going to have to go through. So that made life much easier, you know what I mean, that I was aware those things were going to happen. If I hadn't been told that and suddenly 4 days after being sent home, like, you know… suddenly had serious… … I was actually rushed into hospital after one of the operations I had on my throat, but they did tell me that in… … in rare instances that you could get a bad bleed. It's unlikely but… but he said you could get a bad bleed when you are at home and if you do come straight into the hospital like, yes. So one morning I woke

up three days after I'd had the first operation on my first tonsil and I was like in bed in the morning and I could feel some liquid in my mouth and I put my hand in my mouth and there was blood and I realised that my mouth was full of blood.

INT Yes.

Patient I went out into the toilet and literally it was like… … that was the most scariest bit of all the treatment I've had by a long way. The blood was pouring out of my mouth and I mean literally pouring and I thought I was bleeding to death and my wife had realised I'd jumped out of bed and ran like, because I didn't say anything to her when I got up, and she came running in and she seen all the blood and it was all splashed over the toilet and she… nearly had a fit like yes… she ran and got an ambulance and by the time the ambulance had come everything had congealed like, you know. But although the blood was pouring out it didn't last for long time, I guess. Probably seemed longer than it was. But still quite a bit of blood came out. Then it congealed and my mouth was full of all these like big massive clots like, you know what I mean? So they took me into hospital and I spent a day in hospital and they realised it was one of these unusual bleeds. But he had told me about that. So I was… when it was happening, even though the scare was… God I am bleeding to death here… when it stopped I remembered he'd told me that this could happen like, and might seem worse than it actually is.

INT Okay.

Patient So I was glad he did that, like, that initial… gave me that initial information because it made things a little bit more easy to deal with. If I had just suddenly started bleeding without know that that could happen then I would have been really worried, yes.

INT So did he kind of give you a few options for treatment before… like at the beginning stages?

Patient Yes, well he…

INT Or did he say well we are going to do this?

Patient No, he said he told me I didn't have to have any treatment, he was advising me that these are things that I think you should have, but at the end of the day, it's up to you like, you know what I mean. You can refuse to have these treatments, like, you know what I mean? I wouldn't recommend that you do that, but, it's not that I have just decided you have to have all these biopsies in your mouth, throat, tonsils… in fact

when he, I told you that when he took the first tonsil out, which I had agreed to, and then he took me back in and said “remember I told you we wouldn’t have to take the other one out, I think we need to just in case, but if you don’t want me to, I won’t. It’s up to you, I’m not going to do something you don’t want me to do, because the chances of it having a cancerous tumour in it are quite slim.” It is really slim, it’s a small chance, so if they don’t we’ll never know. So he did give me an option, so I could have said “no… …. after that first time, no way are you going back in there again, that’s it I don’t care!!”

INT LAUGHS

Patient and some people will probably do that I am sure they will, but I trusted him and I knew that people were saying this guy’s a top surgeon and he knows what he’s talking about, you know what I mean? So, if you’re saying I need that, then yes, okay let’s do it then, yes. I will heal eventually and be okay.

INT Yes. So do you quite like to be involved in… when it comes to decisions about your health?

Patient Of course yes, yes. I like to have the proper advice and have reasons for why somebody’s gonna do something – I don’t want to be see as I’m just a guinea pig like and maybe they are using me like, you know what I mean, as an experimental toy. So no, definitely not. So like to, like I say, to have a discussion on why you are doing this, what’s the reasons behind it, what are you likely to achieve by this… and he was very good with that, definitely good with that.

INT And so do you have an example of a previous negative experience with a healthcare professional at any point in your life, not just to do with your cancer?

Patient Well in my job I’ve had lots of negative experiences with healthcare professionals. [Laughs] In general, that was a very different environment, because I was a medical representative like, you know what I mean, and the relationship between medical representatives and doctors like you know what I mean can be fantastic… depending on who the doctor is, or not so good depending on who the doctor is. So there has been experiences in my lifetime where I have been with doctors who haven’t been particularly nice and… … but in general I would say that most doctors are reasonably understanding people, as long as with anything in life, if you treat somebody with respect and treat somebody properly they tend to treat your properly. But like all professions there are good and bad. There are bad doctors out there like, you know?

There is. You know, they don't always treat their patients the way they should do and treat other people, like medical reps as I was at the time. So, yes, so I have had some experiences where someone was very rude like and very horrible and I've seen, I've been in surgeries where doctors have been rude to the patients as well, on more than one occasion.

INT **Yes.**

Patient And I have seen where lots of patients have been rude to the doctors as well. [laughs] It goes both ways like. But my over… but I did that job for 29 years, so I would tell you that I liked it and I had a better relationship with the doctors in a more positive way than a negative way. So generally like, you know, most doctors do a really good job and are in the job for the right reasons… but there are doctors out there that maybe shouldn't be doing the job they're doing, you know, and they can be quite difficult with people. So… …, but generally the trend is pretty good.

INT **Yes. So when it comes to erm… your appointments with Mr (consultant), erm… do you feel perhaps more comfortable expressing certain concerns or issues than others?**

Patient No, not really no, no. I am comfortable like about expressing things, like you know what I mean like. I like to talk things through, I like to get to the very bottom of things. I like to get to understand it myself, like you know, because of my science, medical background I like to know and understand anything, you know what I mean? If there's something I don't know about, tell me more about it, I want to know, like yes?

INT **I mean for example… … what we find with some patients is that they, they feel comfortable kind of talking about physical symptoms and things like that, but they don't feel quite as comfortable erm… raising kind of emotional or psychological issues – do you find that's the case?**

Patient No, I wouldn't find that an issue, no. Personally, right now… erm… if I had personal or psychological issues, you know what I mean, which I haven't had, I'd be quite happy discussing them with people, you know.

INT **You'd feel comfortable raising…**

Patient They have a counsellor in there which you can go to as a patient, you don't have to… I can't remember who… I only seen them once and she asked me would I be prepared

to come and discuss like you know what I mean, any issues I had. I spent about an hour with her, just like I am with you.

INT Yes.

Patient She sort of identified that I didn't really have too many issues – that I was a pretty confident person, with a clinical knowledge about the environment and it wasn't really affecting me too much about going in and so… I just had a nice chat with her, was willing to like tell her how I felt and all the rest of it… and there's no doubt that she's seen patients that like you know were much more concerned about psychological impact like it was having on their health, like you know what I mean, than just the physical. So… no, I am willing to talk about it, but I haven't felt, except for that occasion, any particular reason to talk to anybody about it, you know what I mean. I get enough information from Mr (consultant) when I go to see him to keep me happy like.

INT Okay. So in terms of erm… the appointment on Wednesday – if you could change anything about it, what would you change?

Patient Could I change anything about the appointment on Wednesday… … no I don't think there was anything, no, no. Wednesday went very well. I'd normally say like now get me in quicker, you know what I mean, and I haven't to sit around here for an hour, like, but I understand why you have to wait that long, you know? But still, sitting around in a waiting room for a long period of time, when you've been given a particular time, can be infuriating even if you understand the reason behind it. I'm not complaining because I know there's good reasons as I've told you before like, yes. But that was one where I got in right away, like you know – so how can you complain about that. The investigation went… … so I can tell you now… he wasn't putting anything on there for the sake of you being in there in regards to the session. That would normally be the same, exactly the same. You go through the same rigmarole, I get through the same investigations, a little chat asking about myself. In fact I think he asks me every time "have you retired now" or "you are retired now". He knows I have. But he probably just wants to find out what I've been doing, do you know what I mean. So no, I don't think there way anything, that… in that department. Maybe they should have got my next appointment time right at the end, that's the probably the only negative that night I think, when they put me down as another person 20 years old than I am. But generally the actual consultation with Mr (consultant) went… I came out there feeling really good you know, feeling assured that, you know, that he'd done a thorough job and told me what I wanted to hear, that everything was

going well and erm… look forward to seeing you in 3 months again. In fact, I keep wanting them to say they don't want to see me for about 5 or 6 months. You know, I'm trying to put them off all the time… "does it have to be 3 months" like you know what I mean? It was 2 months, I thought it was 2 months but time goes so quickly and he said "no I'd still like to see you in 3 months" like, you know. So they want to see me more than I want to see them. Not because I don't want to see them personally, because its not a hassle like having to go down there. I already have to go every three months like for blood tests for my other condition like, you know, so that they can keep a check on my platelets all the time to make sure this drug is working like, yes. So I am just going back and forwards to Fazackerley hospital all the time, I am. So when the day comes when they say "oh you don't have to come back for 5/6 months now", but it sounds like from what he said the other night that's not going to be for another year now. He said until next year we'll see you every 3 months and then the… times between appointments will get longer, which shows they are going to be more assured that I am okay like yes.

INT **Yes.**

Patient So no, everything was fine that I am aware.

INT **So earlier I used the term "cancer journey" at the beginning of this interview and what do you think about it?**

Patient What do I think about…?

INT **The term, "cancer journey"?**

Patient What do I think about the term "cancer journey"… … from the very start like yes…

INT **That I used at the beginning of this interview.**

Patient I….

INT **Do you agree with that terminology?**

Patient I didn't even notice that you'd actually said that to be honest. Cancer journey… … see, well you'll get a lot of people, as I said before, if you mention cancer like, you know what I mean, or remind them they've got cancer, if this was my wife sitting in front of you and they remind her that she had breast cancer, she'd be a nervous wreck like. She doesn't like to talk about cancer at all. She really doesn't like to talk about her condition and I know there's a lot of people who are like that. They just like to put

it to the back of their mind and carry on with their lives. So if you did talk to her in those terms, yes I am sure she wouldn't… you know. For me… no, because I am quite okay with the term and because of my knowledge of the medical environment and diseases in general I guess, and erm… you know, cancer has been in my family. I lost my mum and my dad to cancer – my mum in her 40s and my dad in his 80s, but both to cancer like yes. I am the first of 5 siblings to have cancer, so I hope I am the only one, you know what I mean. So… and then my wife like with breast cancer and you think… thank God she's still alive 19 years later. So I have had cancer around me so I have become comfortable with it, you know. So I am quite happy to talk about "cancer journey" or whatever, yes. That's not an issue for me like… but obviously not because I didn't even notice you'd said that. If somebody was worried about that they might have went… they might have reacted maybe yes. "Could you say that in some other way" or… I don't know… do people say that, do they?

INT **Erm… I think generally most of them are okay with it actually.**

Patient Yes. I suppose if you hadn't got cancer it's more scary to talk about cancer like, you know, than when you've actually had it to some extent, you've had it, you've got it now like and you've got to deal with it. You know my wife still obviously I'm saying like won't accept she's got cancer and she's still… you know, on that journey ahead like you know what I mean. Hopefully it's not gonna come back now like, you know. She'd certainly be a lot more comfortable now than what she would have been before she got cancer. If you had mentioned cancer or anything like that to her, you know what I mean, and she would have run a mile, yes. Then she… … she then was diagnosed you know with a very serious cancer as well, more serious than mine and erm… she was a nervous wreck for many years. Then she realised that she was getting over this… you know… 19 years later. She's more coping with it like you know, so the longer you have something the more you can live and deal with it. You've got to, you've got to accept it haven't you, you know what I mean. Like worrying…. I… I'm a very strong person than my wife so I don't tend to be a worrier, I don't tend to get stressed out too much like yes. We all get stressed out times for various things, but don't get stressed out if the [unclear] isn't working right, there are more important things in life like, you know what I mean. If you had lived around in one of those flats in London, you know what I mean, then you'd be more stressed, you know what I mean, assuming you were still alive like, the people in there. There are things in life that you need to get stressed about… you know, your job and your studies and the all the rest of it are important, and stressful… but don't let them affect your health. I never try to let anything affect my health like that. So I came out…

when I was first diagnosed…it wasn't what I wanted, but I wasn't going to let it affect me, I am going to be strong and I believe, you know what I mean, that the power of the mind, if you are really strong and don't stress over an illness you are more likely to get over it, I think. So it's not just the medications and a lot of medications, because I've been looking at them in my job for 29 years, but it's also about the state of your mind as well. How strong your mind is and how do you relate to other people as well and how do you talk to other people, do you know what I mean, and the things that you do with your life… if I just sat around worrying about my cancer I wouldn't be getting anywhere like, your life wouldn't be worth living. I didn't even think about it at times. If somebody wants to talk about it, like, if someone rings up and says "how's your… how's your cancer now" I'm quite happy to talk to them about it. My wife wouldn't be as happy to talk about it, you know what I mean, she would rather people didn't talk to her about it. But I am quite happy. If you want to talk about it, I'll tell you like I am with you. I didn't feel uncomfortable at all telling you anything I told you today, but I don't go around thinking about it. I just… day to day, I just totally forget I've even got this, you know. I have come to notice when I look in the mirror and I see a scar down my throat and then I think like, you know, it doesn't look too bad like, you know what I mean, it's not that noticeable, and I'm healthy like, you know. It could be worse, if I hadn't got that done. What if I'd just left that, you know? So… it's not doing me any harm and I've got no symptoms. I am sure eventually it would have caused some problems like, would have eventually broken out of that lymph node and spread like, you know what I mean. So I look at the positives. Whatever, for whatever reason I was meant to get this, but I was also meant to do something about it at an early stage and deal with it, so I feel very positive indeed.

INT **Okay, that's good. So can I just ask you a few questions quickly before we finish…**

Patient I'm gonna have to go in about 5 minutes anyway.

INT **I just want to ask you a few questions about your education and erm.. career and then we're done.**

Patient Okay.

INT **Erm, okay, how old were you when you left formal education?**

Patient 22

INT **So erm, so what was your highest qualification then?**

Patient Degree in Micro Biology BSC

INT So that was a Bachelors

Patient BSc degree yes. Micro Biology.

INT Erm… so you are currently retired?

Patient I retired at 60 yes.

INT Erm… so before then erm… which job did you spend the longest in, which career?

Patient About 6 months after I finished my degree in 1978 I came to Liverpool immediately, I was coming here for a couple of weeks holiday but I decided to stay longer, and then longer and longer. Then I decided well I'd better get a job now, you know. So I got a job in the NHS as a Micro Biologist in a lab and I did that for 9 years. Then I got sort of a bit frustrated with that like and the money wasn't very good, the career options weren't very good. Erm… I thought I need to spread my wings and do something else. So I decided to go into the pharmaceutical industry, so I spend the next 29 years of my life in the pharmaceutical industry. Mainly in the sales environment, medical sales.

INT Yes.

Patient For the last 10 years, last 15 years I was working as a HIV specialist. Then I got to 60 and I decided that I'd had enough of… talking about stress you know what I mean… I wouldn't say I got overly stressed, but it was a stressful environment and quite demanding and I thought I'd built up a reasonable pension and thought "I've had enough of this". So I retired early and I've been enjoying it every since.

INT Yes.

Patient I have no regrets. I've got a lot less money… but my life's happier. [laughs] I used to do a lot of driving and travelling as well and away from home a lot like yes. Particularly when I was in HIV I was all over the world like, you know, with the job. Some of it has been fantastic. I spent some time in Africa, which was great. I was in Kenya and Cameroon. I worked on projects like, you know what I mean, that were all over. Sub Sahara and Africa were the two countries I visited. But a lot of it was on the phone and Skyping people and stuff. So yes, I've had an interesting…. I've never been unemployed.

INT That's good

Patient And now, even when I'm retired I'm still doing 2 days a week work. I'm getting nothing from it but I enjoy it so… I really enjoy that. I enjoy that more than when I was enjoying my job. In the last 5 years I was getting a little bit pissed off with my job because it was becoming more and more demanding and it wasn't the same environment that it used to be. So I got out at the right time I think and I enjoy what I'm doing now.

INT That's good. So are there any other points you'd like to talk about before we finish up?

Patient No, I don't think so no. I think you've covered quite a lot like yes.

INT Okay, well thank you for taking part.

Patient I hope that's been useful to you, you know what I mean.

INT Oh definitely. It's been a big help.

Patient I don't think you'll get too many patients with a story like that, like, you know what I mean. I'm not trying to be particularly special like, you know what I mean, but it has been a bit unique part of that story like.

INT A very interesting case yes.

Patient And it's not sort of [unclear] as Mr (consultant) would say the same. I'm not the typical type of patients he sees every day, you know what I mean. But maybe when he sees people like from my background, with that sort of knowledge, they can get sort of more involved in the treatment like, in much more depth like than the ordinary person off the street. I am quite happy, everything's going okay. I'm feeling good and I wish you well with your studies. If there's any way that I can help you… in the future again, just… you've got my phone number?

INT Erm yes.

Patient You've got my email address so… give us a ring. Honestly, I'm happy to help you if there's anything else you want me to follow up with like yes.

INT No worries.

Patient You look after yourself.

END

Appendix 10. Example telephone interview transcript

Patient: 9 **Consultant: 3**

INT **Okay so to start with I would like to learn a bit more about you.**

Patient Yep.

INT **So could you tell me about what has happened in your cancer journey up until now?**

Patient Right it must be when I first noticed I was sat out in the garden, I woke up from a little snooze and I noticed a lump on the side of neck. I have not previously had cancer but my mother-in-law had lymphoma.

INT **Yeah.**

Patient Erm…the lump came up so quickly I thought 'oh that's a bit strange' so I was a bit perturbed by it, went to see my GP and he referred me to Mr (consultant). Erm…and I went along to Mr (consultant)'s clinic and at first he said, he believed it to be a branchial cyst although he was a bit concerned because of my age. Erm we did a needle test, inserted a needle into the cyst and drew fluid from it and that came back initially negative so comes away and then I go back to see him I think 2 weeks later and he said there was cancerous tissues so he arranged for surgery to do removal of the cyst and to do a cold section. The surgery was completed and it was confirmed that it was cancer and erm we would have to go back into the surgery. The cyst was the secondary site and they identified the primary site at the base of the tongue. I believe it was due to some virus. I had to wait erm for the second lot of surgery because of the scarring from my original surgery on the cyst, which he believed may be problem so we waiting for the original wound to heal and then he brought me into surgery, opened my neck up, removed whatever he removed, I believe it was neck muscle, artery and erm all old scar tissue from my original operation. Erm after the surgery it was a 6-week course of radiotherapy 5 times a day sorry once a day for 5 days of the week at Clatterbridge and that was just radiotherapy. And that finished in December. Erm…the surgery has left me with permanent injury to the neck which has affected my work and I still have problems with my shoulder which fatigues quite readily. The radiotherapy side of things affected me quite a lot because I lost a lot of weight and I still suffer from dryness in the throat and soreness in the throat area of a morning when I wake up and throughout the day and it's altered my diet etc. etc.

Erm…and then we just, Mr (consultant) and my Oncologist, Mr (oncologist) once every 3 months now. That's for two years and I am under their supervision for a total of 5 years I have been told.

INT Okay.

Patient That's it really.

INT Okay so erm were erm any of your family or friends involved your cancer journey?

Patient Yeah my wife, obviously the kids I have got 2 daughters.

INT Yeah.

Patient One at university and the other is just doing her GCSEs at the moment. Erm…Mr (consultant) and Mr (oncologist) were very positive like from the start so erm after the consultations my wife and I came back and…it's not a positive set of mind but it is erm say on the positive side of things, there were negatives because we were worried about what or where the cancer had spread but I was told after the scans that it was confined to those two spaces.

INT Okay.

Patient However as with cancer one doesn't know what's going to happen and once the sites are erm…invaded basically by the surgeons and the radiotherapy so it's just a watching brief at the moment, but they are very positive and I came out of the initial meeting erm not happy but erm you know in a positive state of mind.

INT Yeah. So erm your wife was in the erm appointment which I sat in on, does she usually?

Patient Yeah my wife comes to every appointment.

INT Yeah.

Patient At the time err I have retired from the police service but my wife was in the last 2 months of her police service.

INT Yeah.

Patient I have undertaken a new role within the police after retirement as a Detective; I came back as civilian staff.

INT Ohhh.

Patient Doing dismantling cannabis farms which was quite labour intensive.

INT Yeah.

Patient But I obviously had to go off long term sick so but the job stood by me and I have now got a newer role cause I can't go, as we say in the police, forward facing, that means I can't meet general people of the public etc. so I am in a back role now, back room role doing the civil litigation. So in a way I come out of it in a better job shall we say than doing the…

INT Ohhh okay.

Patient …and when I was undergoing the treatment the police were very good erm and the wife was able to stay off in the last 2 months of her, well she would go in every now and again but they were very positive and they just said take as much time off as you need because the journey to Clatterbridge every day was a bit taxing…err the radiotherapy it does take it out of you physically.

INT Yeah.

Patient Not so much emotionally but physically it drains. And then after the radiotherapy it just got worse for about a month and I was in real real pain with my throat, I couldn't eat, I couldn't drink I couldn't swallow so…erm…but she was there all the time for me and err she helped me through it, as did the girls. I mean (eldest daughter) was at university to she was in the digs at the Philharmonic Hall there so she would come home whenever she could. My youngest tended to the wound on the side of my neck so they were all very positive so it helped me on my journey.

INT Awwhhh that's nice. Erm…so erm could I ask you a few questions about the appointment which I sat in on last week.

Patient Yes. Yes crack on.

INT So erm how were you feeling on that day before the appointment?

Patient Well it's funny really because I get apprehensive because it's always in the back of your mind that it's returned.

INT Yeah.

Patient And it's usually a couple of days beforehand I go slightly introverted I think the missus would call it. Erm because I know that he is going to perform that insertion of the camera up my nose which I detest intentionally.

INT Urgh yeah…*chuckles*…

Patient *Laughs*…it's a necessary evil.

INT Yeah, *laughs*.

Patient When I sit down with him he is always very amenable, erm he is very positive. I just thought he is quite talkative. He did ask a couple of questions, one question that he has never asked before which is do I get earache which has felt a bit iffy but when he was physically examining my neck, which he does every time, he paused and I thought 'he has found something here' but then he carried on…erm but it's just the apprehension of going there erm…it's not too bad with Mr (oncologist) because he doesn't perform any invasive procedure he just kind of looks down the throat but with Mr (consultant) it's that camera that does…it does me in but apart from that it's great you know.

INT Yeah. *Laughs…*

Patient And when you come out, when he has given me it's a positive and I think you are progressing well it's like a senses of elation afterwards.

INT Yeah.

Patient So but it is what it is and he is very good, very amenable and he…as far as I know he is very truthful and the surgery that he undertook erm it was just fantastic as far as I can see anyhow.

INT Yeah. Erm so was there anything you were worried about or wanted information about erm for the appointment?

Patient It was just erm as you saw I have got a lump on the back.

INT Yeah.

Patient Now I have had that before and I described it, it went into a multi headed, like a **[unclear 11:18]** boil and that went down so I have been to see my GP and he has referred me to excised so I am just waiting for an appointment there. The wife was saying just to put your mind at rest just ask Mr (consultant) and good enough he had

a look and he backed up the GPs theory that it is a sebaceous cyst but it's there in the back of your mind any lumps or I start scratching at any spots or anything like that it's always in the back of my mind that it may have returned but he puts my mind at rest any time I go, as does Dr (oncologist) so, there is no questions to be asked. I think they explain everything to you.

INT Yeah.

Patient If there is anything there then they won't hold anything back as he didn't at the initial diagnosis.

INT Okay.

Patient This is what I want to do, this is what it'll be and you may have this problem and he fully explained the surgical side of things and what possible problems I would face in the future and by enlarge what he said has come to fruition. I have got numbness in my shoulder and I have got numbness in my neck and its going but it is a very long process.

INT Yeah. So erm do you feel like you get enough information then?

Patient Yeah, I…from day one the information has flowed. You know he told me what it was, he told me where it come from, he told me what the problems were, and if I am honest we met with the Macmillan nurses and I have never used their services but it was always there and the continual treatment post operation erm…I had a nurse coming out to the house to tend to the wound to remove the staples.

INT Oh yeah.

Patient I couldn't fault it. The stay in hospital I was there for 2 days and that was only whilst the surgery, the drain that was put in to err keep the wound clean I was in there until that cleaned and then I was released, which I didn't mind because I would rather have been home anyhow. You tend to go into slightly reclusive erm state of mind. But apart from that everything else was fine.

INT Okay, so what do you mean about reclusive state of mind?

Patient Err…I had my family round me.

INT Yeah.

Patient And friends and colleagues who would say do you mind if we come round and I would be, well not at the moment I don't want to see you cause I had lost that much weight going on and I was in that much pain I couldn't do much I was just sat in the chair really. Erm…I couldn't sleep of a night so I really didn't have much self-esteem or body image at the time, no positive body image.

INT Yeah.

Patient But I asked them to just stay away which they respected but once I was well enough I would tend to go out, visit work, see my colleagues and then I was visited by the bosses, which they have to do, they call it the welfare visits and two senior bosses come out and spoke to me etc.

INT Yeah.

Patient And again they were very positive you know stay off as much as you want blah blah blah but once I got over the initial loss of weight and I was getting back on my feet again then friends would come round and you know talk about the experience erm and it slightly altered the way I look at life at the moment. I don't go out as often…

INT Ummm.

Patient Cause one of the triggers erm can be alcohol, I don't smoke, I didn't drink to excess so it's slightly changed our outlook, certainly we don't go out as much as we used to erm but once I am on the straight and narrow it's fine it's back to normal though socialising at work etc.

INT Yeah.

Patient That's it really.

INT So erm how do you feel about how the appointment went erm on Wednesday?

Patient On Monday it went as well as I could expect erm as I said you know what to expect the tube down, the camera down the nose and then he feels my neck erm which is still a bit of a problem because of all the nerve damage etc. You wouldn't have been able to see my face but its cringe worthy when he touches my neck and probes etc.

INT Ummm.

Patient The wife finds it quite amusing that **[unclear 17:06]** but there you go. But he has to do that and he is as gentle as he can be, he needs to examine my neck and see if

there is any lumps, bumps or cracks that he can find and then he will take it from there but as you see he is very relaxed, actually he puts you at ease – that's why we make a joke about me going into the chair.

INT **Oh yeah…*laughs…***

Patient An evil chair of torture but it's one of them…it…it…when I first went there he was asking what I did for a living and I told him I was in the cannabis dismantling team, what do you do?, dismantle cannabis farms and…you know it's probably not something that he has experienced before not a lot of people have but he made a laugh and a joke about it and because of the surgery etc. I couldn't go back to that job.

INT **Yeah.**

Patient The Force doctor was trying to make me go back and he said no you are not going back to that, cause we have to what you call personal training, protective training, which is basically fighting. He said "you can't do that".

INT **Yeah.**

Patient **[unclear 18:27]** the right hand side of your neck, if you are in a chokehold you are going to faint straightaway so…

INT **Yeah.**

Patient …so it's one of them so it has changed the job description that I was in but it's one of them you just have to crack on get over it and move on.

INT **Okay.**

Patient The meeting it's fine like I said before I get apprehensive but once I have been that's it for another 3 months or 2 months and I go and see Dr (oncologist).

INT **Yeah.**

Patient You know, they are both experts at what they do and you can't argue with them because they know what their expertise is all about and I have got to have faith in them and I find that they are very positive with me so I am more than happy with them.

INT **Okay. Erm…so erm…do you remember when in the appointment you mentioned your sort of dry throat and stiff neck.**

Patient Yes.

INT How did you feel about Mr (consultant)'s response to that?

Patient It's…it's the norm now because every time I go there is dryness, the soreness but it's becoming less and less.

INT Okay.

Patient They said then you would have permanent nerve damage, which I understand, but sometimes it's worse than other times.

INT Yeah.

Patient And at first after the radiotherapy it was explained to me that I may not get all my taste sensation back. They said my throat would become sore, would become dry and I don't know how many throat cancer patients you have come across during your research but they refer, the doctors refer to us as "water bottle carriers" cause after the radiotherapy everybody who is in there has bottles of water…

INT Yeah.

Patient …**[unclear]** that quickly. So that's becoming less and less.

INT Okay.

Patient As I say my taste sensations have changed and my diet has changed. Erm…but whereas I could eat certain foods I don't like them anymore.

INT Yeah.

Patient I have tended to have gone to things I ate prior to the surgery I wouldn't even contemplate eating now. It is strange though how the taste sensations have changed.

INT Ohhh.

Patient Other than that you just have to crack on with it, the fatigue in my shoulder is an ongoing thing err I do a lot more exercise than I used to.

INT Yeah.

Patient To try and build up the muscle mass again in my shoulder because I lost a lot of muscle mass again round my shoulder because I lost of muscle mass where they

excised and dug in underneath to remove nodes etc. erm…I have been given exercises to do by the physiotherapist.

INT Yeah.

Patient With the physiotherapist at work and he basically said after a number of sessions, it's down to you now I can do no more so normal work life is sat in front of a computer.

INT Yeah.

Patient So when I come home I do physical exercise, press ups, sit ups, stuff like that just to keep the muscle building going but it's still there, I know it's there, I am conscious of it.

INT Yeah.

Patient But as they said it would be no more than that. They have given me a timescale and basically it's sticking to that timescale.

INT Yeah. So Mr (consultant) erm asked you about your shoulder didn't he?

Patient Yes. Yeah they ask erm…every appointment it's the throat, the shoulder erm weight erm fitness and general lifestyle really.

INT Okay.

Patient Erm…because the lifestyle thing, I am very conscious cause he said "do you smoke?" and I have never smoked.

INT Yeah.

Patient Do you drink alcohol, and they would all point to this particular cancer, so it tends to put you in a different mind-set shall we say.

INT Yeah.

Patient And that's what I have done, I have never taken up smoking and I never will.

INT No.

Patient But the shoulder it is what it is, he will touch it, feel it, as you saw he was making me move it up against the muscle resistance – but what I do find is fine motor skills, I do fatigue on my right hand side quite a lot if I am doing fine motor skills, you know like, and it's absurd like but like chopping vegetables or stuff like that.

INT Oh right.

Patient It really really was hard in the beginning but it's easing off and I am able to do a lot more, like painting walls.

INT Yeah.

Patient Etc…it's those fine motor skills that the nerves are still not joined up properly.

INT Yeah.

Patient That causes a lot of fatigue but we just crack on.

INT Okay. So does Mr (consultant) has he ever offered anything to help with the shoulder or?

Patient Erm…he he just says are you doing your exercises, which I am not…and that's it really. If I asked him no doubt he would advise me and if I asked him for physiotherapy no doubt I would get that physiotherapy because he has always said, if you have any problems then if you don't want to contact your GP then contact the clinic and we will see you as soon as possible. Which is always reassuring.

INT Ummm.

Patient And he said because I am a cancer suffering, and it sounds really bizarre but you do tend to get a better best treatment you are seen quicker than you would normally be seen at the local GP. I think that's possibly down to guidelines etc. cause I was seen within of 10 days of when it happened the lump. Erm…but as I say Mr (consultant) would, no doubt if I had a problem, if I went to him or Mr (oncologist) then it would be expedited.

INT Yeah. So do you feel quite erm comfortable erm you know erm asking them anything?

Patient Errr yeah, I mean because you hear all problems with the NHS etc. it is quite humbling really that they turn round and say anything you want come in.

INT Yeah.

Patient When you know that other people are more deserving of it but then a lot of people say well you have been through a journey that's quite horrendous really erm…you have paid your stamp all your life so it's…it's what you would expect and the treatment

I have had so far is first class. I can't fault it in any way, especially from the surgeon and the oncologist and even at Clatterbridge the radiotherapists were brilliant.

INT Yeah.

Patient Yeah it was first class care and attention, you can't ask for anything more but as I say it is the communication is good.

INT Okay.

Patient There is not ifs and maybe's, you are going to get it.

INT Oh that's good. Erm is it usually Mr (consultant) who you see on your review appointments?

Patient Erm normally yes erm…I have seen I think it's two different surgeons erm…one who assisted Mr (consultant) and I can't think of his name.

INT Ummm.

Patient And a second consultant, and basically they just did the same as Mr (consultant), although they haven't got the intimate knowledge although the surgeon did cause he was there, he drew on my neck where they…I mean he visited after he was doing the rounds and Mr (consultant) saw me just prior to discharge so it's not a problem.

INT Okay.

Patient They are working off notes so; I have a good lot of confidence in them. If they find anything they are going to tell me and try and sort it.

INT Yeah. Erm so erm there was a bit of small talk in the appointment.

Patient Sorry there was a bit of what?

INT There was a bit of small talk in the appointment?

Patient Yeah.

INT Is that usually erm the case or?

Patient Yeah cause erm I think initially cause as I said I was a serving police officer and my wife is a serving police officer, it's a talking point and what I did as a job, the cannabis dismantling as I say it is so far out of the norm it is quite amusing to him when I said what I did for a living. Erm…but the small talk is there just to break it up I think and

to bring a little bit of humanity into the process because it can be very clinical I think and if it is clinical I don't think it puts people at rest.

INT Ummm.

Patient So to be fair and I try and make a bit of a laugh and joke about it and I am sure he appreciated me not being too serious although I know it is serious I think being an police officer for 30 years it gives you a little bit of black humour.

INT *Laughs…*

Patient And you know we have laughed at different aspects but that's just the way I am and the way the police force has given me that ability to look at bad things in a, shall we say, in an enlightened way.

INT Yeah.

Patient To bring the process of communication easy. Erm…dealing with death and all the rest of it…it helps to bring not so much humour into it but a bit of empathy and a bit of realism and you can only be morbid for so long and then you have got to get on with life and you know the initial diagnosis was it's cancer. It was devastating at the time.

INT Ummm.

Patient But again he was positive. Erm…I will do whatever I can and I am pretty positive. I mean he said "I will cure you", and touch wood so far he has been really good to his word. But there is that small talk you build that little bit of a rapport up.

INT Okay.

Patient Although you have limited time but he comes across very erm…very professional.

INT Yeah.

Patient Very human shall we say.

INT Okay.

Patient **[unclear 30:40]**

INT It was within the appointment erm the physical exam started quite soon into the appointment.

Patient Yes.

INT How do you feel about that?

Patient I know that they have limited time that you are allocated erm that clinic especially on certain days they have people from the Isle of Man take their priority.

INT Yeah.

Patient Which I wholly acknowledge that but they can only do so much in the allocated time and he went straight into it err and I had no problems with that.

INT Okay.

Patient The sooner I am in there the sooner I am out of there and I am in a more positive frame of mind.

INT Yeah.

Patient But I know what to expect now erm…as I say I just had a camera up my nose and down the back of my throat which I don't like.

INT Yeah…*chuckles…*

Patient But it's a small price to pay.

INT Yeah.

Patient It is what it is. Erm and he does it well.

INT Okay. The waiting room wasn't too busy at that time was it?

Patient No, it's surprising it normally is rammed erm…sometimes you have got to stand outside in the corridor or go down the other clinic and sit there and wait to be called.

INT Ummm.

Patient But as I said the Isle of Man patients take precedent or ambulance takes precedent.

INT Yeah.

Patient I mean one incident there, there was a prisoner from prison being brought in so you know it is what it is, I fully accept that but it's time off work for me but work have no problem with cancer sufferers they understand that the unique nature of the illness and I can take as much time off as I need.

INT **Oh that's good.**

Patient To see my consultants apart from that it's the NHS and unless you are private you are going to have to wait.

INT **Yeah…*chuckles…*Erm so erm could I ask you about your experiences with health care professionals in general now.**

Patient **[unclear talking over each other]** go on sorry.

INT **So erm not just your kind of encounters relating to your cancer but just kind of all in general.**

Patient Well it's only the second time I have been in hospital.

INT **Ummm.**

Patient Erm the GP, I very rarely before now visited my GP and I have always found him very approachable and various, and if I did attend with various matters and through the experience in hospital, I was in hospital for 2…after the second op 2 night, the first op err…1 night, they communicated everything well. I couldn't fault them even coming round from the anaesthetic err…it was a bizarre situation obviously I was still under the effects, I really couldn't fault the treatment.

INT **Okay.**

Patient The food could have been a little bit better but at the time I couldn't eat anyhow and they are trying to force this stuff down you and physically and mentally I just couldn't do it. Erm…there was a slight bit of bullying but…

INT **Oh…**

Patient They try to get you to do something to keep the weight up and not to use erm…calories and fat etc. and then from there err…with the radiologists they were brilliant, absolutely superb, the girls at Clatterbridge.

INT **Yeah.**

Patient And then I had a dentist obviously because of the unique nature of where the cancer was I had a dentist appointment who outlined all the possible problems I have and can have with my teeth.

INT **Yeah.**

Patient And then I went to see my own dentist and no problems there, she has stipulated that if there is any problems, any extractions then I have got to go back to Clatterbridge because of the problems that the radiotherapy would have caused to my jaw and my teeth and to have an extraction I have got to be under the general anaesthetic, so there is not a problem there. Again they were very positive and didn't hold anything back.

INT Okay.

Patient Even the nurses that came out to see me err post-operative were great. All was positive with them.

INT Okay. So erm do you have erm an example of a particularly negative experience which you have ever had with any health care professional?

Patient Err…to tell you the truth no…*chuckles* no…*chuckles.*

INT No.

Patient What I said before you know with previous bullying…

INT Ummm.

Patient It was not bullying but cajoling, I know where they are coming from but just physically and mentally I just couldn't erm approach eating anything err…the surgery wasn't too bad but after the radiotherapy it was horrendous.

INT Yeah.

Patient And there was no negative attitudes as far as I can see erm when dealing throughout since I was diagnosed with the cancer and even prior to that erm…no everybody was being so professional and kind and prepared to put themselves out.

INT Okay.

Patient Erm…and I know people have bad experiences but everybody is human, I dare say when I was in the police I was pretty awful at communicating sometimes.

INT *Laughs*

Patient But that's just individual circumstances.

INT Okay.

Patient and incidents.

INT So on the other hand then erm could you give an example of a particularly positive experience with a health care professional.

Patient Again with Mr (oncologist) and Mr (consultant) it's very very positive you know I can't say anything negative about them, erm…he has been so free with his information and if I felt that I needed to speak to him then I am pretty sure he would sit there and listen.

INT Yeah.

Patient Even or call him, you know you have so many questions going on when the initial diagnosis came about he just listened to us asking questions. It was a bit of a shock and once we had had the diagnosis we come away, next time I went back we asked all the questions and pre-operation he fully explained the procedures and as you know it was all positive, I can't…I couldn't fault it in any way.

INT Oh that's good.

Patient He is just so talented, I mean obviously you are very apprehensive about what, he is going to cut my neck and where he is going to do this, he is going to do that and then that that was the first operation and then I have got to go back again…you know the scar is going to be much bigger etc. etc.

INT Yeah.

Patient But again he was positive. It is what it is, you are going to have to bear with me we couldn't have foreseen what, where the cancer was, what it was.

INT Yeah.

Patient Everything else **[unclear]**. I said before that there was a cancer there. What he said at the time was "it's something unusual but bearing in mind your age and it's a brachial cyst but I just want to make sure but they found it was cancerous after a cold section and then that's when said "I am going to have to go in a second time and root about and take this and do this". But he was positive there was nothing negative.

INT Okay.

Patient **Unclear telephone line crackly…**you know it was one of them, nobody is god as you know.

INT Yeah.

Patient This is what you have got to work with and we took it from there.

INT Okay. So erm when it comes to making decisions about your health care.

Patient Yeah.

INT How involved do you like to be?

Patient Ahhh…as much involved as I can. I mean they baffled me with all the scientific terms but at the end of the day he describes what was going to take place in layman's terms.

INT Yeah.

Patient What the consequences are and what the long-term effects are. Erm…A, B and C it might be C, D and F but these are the main problems.

INT Okay.

Patient Because he explained pre-operation what the risks were as well because of where the cancer was erm…permanent damage to throat, speech, taste all all that was explained in layman's terms and that was great. I knew where we were going and what we were going to find but since then again it's fully explained and if I have any problems I just have to ask and it's explained again.

INT Okay. So erm were you, did you kind of get a say in deciding what treatment you were going to get or was it Mr (consultant) kind of making the decision?

Patient Well Mr (consultant) said at first we were going to do the surgery and then we are going to go down the radiotherapy and then he said, he stated that there is a discussion group forum of interested parties and it was suggested that I undertake radiotherapy and chemotherapy.

INT Okay.

Patient But he was of the opinion, I think Mr (oncologist) was of the opinion that the chemotherapy was not necessary.

INT Okay.

Patient And so we went with just the radiotherapy. They explained the reasons and obviously being a layman I went with their judgement.

INT Yeah.

Patient They explained why they didn't think chemotherapy was appropriate and what the possible side effects would be of chemotherapy so I just had to rely on their expertise and professionalism and that's the route we took so it was just the radiotherapy. I am glad in a way because the radiotherapy was bad enough and I don't know have to think about having chemotherapy cause I work with a lady who had breast cancer in our office and she is basically at the same stage.

INT Yeah.

Patient She had a little bit of chemo and she said it's far worse than radio so it's it is what it is and erm…I can only go with what they recommend. If I had requested chemo and wanted a second opinion I am sure I would have got it.

INT Okay. Erm so erm in terms of you said you felt like you could express any concerns to Mr (consultant) if you felt you needed to.

Patient Yeah.

INT Erm…do you feel more comfortable expressing certain concerns than others or?

Patient Well there is not erm…some concerns, I just feel comfortable in his presence. When I go there he puts you at ease. As the Mrs says he is very debonair.

INT Yeah…*chuckles*…

Patient So it's one of them, he puts you at ease and you feel like you can interact and he has got empathy of what you are going through.

INT Okay.

Patient Erm…I have no, if I have a concern then I will ask it straight out because I don't know what is going to happen and again if, when I said previous if you have any bumps, scratches, anything you are not happy with then phone up and we will get you in and we will have a look and we will tell you. You see that bump he said just take your shirt off and I will have a look at it.

INT Yeah.

Patient And then he said it was a sebaceous cyst nothing to worry about and then he said "is that what your GP told you" and it is what the GP told me. But it's just that reassurance that you can ask and he will act on it.

INT **Oh that's good. So some, we found that some patients feel more comfortable kind of erm asking the doctor about physical problems but not quite so comfortable with talking about the kind of emotional and psychological aspect of things.**

Patient Yeah I mean that…because of what I said previously I have my family round me and they helped and (wife) was there practically every day erm…apart from going **[unclear 45:51]** erm it…I didn't think I needed to speak about any emotional or mental problems I had.

INT **Okay.**

Patient Erm but I know the assistance is there, the Macmillan nurses when we were initially being treated, they said if there is any problems just give us a ring. Cause you know the care lines are there but I never felt I needed to go that far cause erm I know erm my son suffers from chronic pain and long term illness and I see what he does and you know I can interact with him and ask him and see what he has gone through.

INT **Yeah.**

Patient And it's just the backup you have got with your family you know that if I have a problem then I can discuss it with (wife), if she hasn't got the answer then we would obviously go elsewhere.

INT **Okay. Erm…okay so erm in terms of the appointment on Wednesday.**

Patient Yeah.

INT **If you could change anything about the consultation erm what would you change?**

Patient Erm again not the tube down my throat.

INT ***Chuckles*…**

Patient And my nose I would get rid of that but I know it's essential because he needs to see the site where the primary cancer was.

INT **Yeah.**

Patient And take photographs to compare at three monthly stages to see if there is any sign that it has returned. Apart from that I wouldn't change anything.

INT Okay.

Patient It is at the end of the day a massive reassurance once you come out of that consultation room and he is positive. It is, it makes you want to I don't know I can't describe the feeling when you come out, you think that's another one out of the way.

INT Yeah.

Patient Yeah so it's just a relief really.

INT Okay. Erm…so erm…earlier in the interview I used the term cancer journey.

Patient Yes.

INT What do you think of that term?

Patient Err…it is a journey because from going there with a lump on the side of my neck to what I am now you go through so many different physical and mental and emotional stages. Physically it was very hard, not so much after the surgery but certainly after the radiotherapy. They surgery there wasn't much after care, whether Mr (consultant) is a brilliant surgeon but there was very little pain afterwards.

INT Oh okay.

Patient The main pain that I had was after the radiotherapy and obviously cause you can't eat, you can't drink, every little aspect of swallowing or anything like that was just torture the initial 2 to 3 weeks after the radiotherapy had finished.

INT Yeah.

Patient And it is a journey through all those aspects but you come out of it and although it is still ongoing because you have always got that thing in the back of your mind thinking well it's tomorrow the consultation with Mr (consultant) is tomorrow so it's just that apprehension.

INT Yeah.

Patient But again as I say the journey perfectly describes it.

INT Okay.

Patient It's like a rollercoaster of emotions.

INT Yeah.

Patient One day up next day down.

INT Laughs…

Patient Again it's the family balance and people close to you help you through it.

INT Okay. Erm…so erm is it alright if I just ask you a few questions about your education and employment?

Patient Yeah.

INT Erm so how old were you when you left formal education?

Patient 16.

INT Okay. So what is your highest qualification?

Patient Erm…a foundation degree police studies but prior to that it was a err…a certificate of engineering. I was at sea for 10 years prior to joining the police so I was an engineer.

INT Oh right.

Patient And I got a senior watch keeping certificate. But after school it was 10 years at sea and then obviously I done a foundation degree with the police but I didn't go on to do the full degree.

INT Yeah. So was that a university degree?

Patient Yeah it was at John Moore's yeah.

INT Oh right. Erm…so erm…you said you currently work in the police force?

Patient Yes.

INT What was it civil litigation something?

Patient Civil litigation investigator is the sexy term but basically fighting complaints err there is people wrongfully arrested.

INT Okay.

Patient They claim, **[unclear 51:58]** Chief for money so we basically try and fight the claims based on law erm and whether or not they are trying to pull the wool over one's eyes.

INT Yeah.

Patient I have only been doing that for 8 months now and as I say because of the illness I couldn't do the cannabis dismantling any more.

INT Yeah.

Patient So that's civil litigation yeah.

INT So what career did you have for the kind of majority of your life?

Patient Erm the police erm uniform and then most of my career was in covert policing and doing major crime investigations.

INT Oh okay.

Patient Drugs and firearms and financial investigation.

INT Oh okay. So was that like as a Detective or?

Patient Yes.

INT Okay.

Patient I was Detective yeah. It's basically surveillance and targeting organised crime groups importing and distribution of controlled drugs and firearms.

INT Ohhh.

Patient I was kept quite busy in Liverpool as you can imagine.

INT *Laughs…*Erm okay so is there anything else you would like to erm mention before we end the interview or…

Patient No it's funny speaking about it because I have never sat down with errr apart from (wife), my wife and never spoke about, as you say, the journey.

INT Yeah.

Patient Err…I have had to describe what I have gone through a couple of times to erm…the force doctors and stuff but not in so much detail.

INT Yeah.

Patient It helps speaking to people about it.

INT Yeah.

Patient Now I am, I just hope this assists you in any shape or form.

INT Oh definitely.

Patient If you have any further questions or you think of anything feel free errr and we will sit and discuss or whatever.

INT Okay thank you.

Patient As say if there is anything you feel you need to ask then feel free.

INT Thank you.

Patient Without going through it you can't express what it's like to go through it, it's like I say the pain in the throat is terrible but it is, you can't explain it it is difficult to describe what the 2 weeks after radiotherapy is like I am sure you have spoken to people who have all had the same.

INT Yeah.

Patient It is horrendous but it's worse than horrendous but you get through it and here we are now.

INT Yeah…*chuckles…*

Patient I have got nothing else to ask you.

INT Erm well thank you for erm agreeing to take part.

Patient No anything that you need, anything you can think of then feel free erm I will always discuss things and I do hope it does assist you in your PhD.

INT Brilliant thank you, it's definitely been a big help.

Patient Brilliant.

INT So as I said obviously this is confidential.

Patient Yes.

INT So erm yeah that's it then erm thank you again.

Patient *Chuckles*…not a problem thank you.

INT Okay.

Patient Okay.

INT Okay cheers.

Patient Alright thanks very much. Take care now.

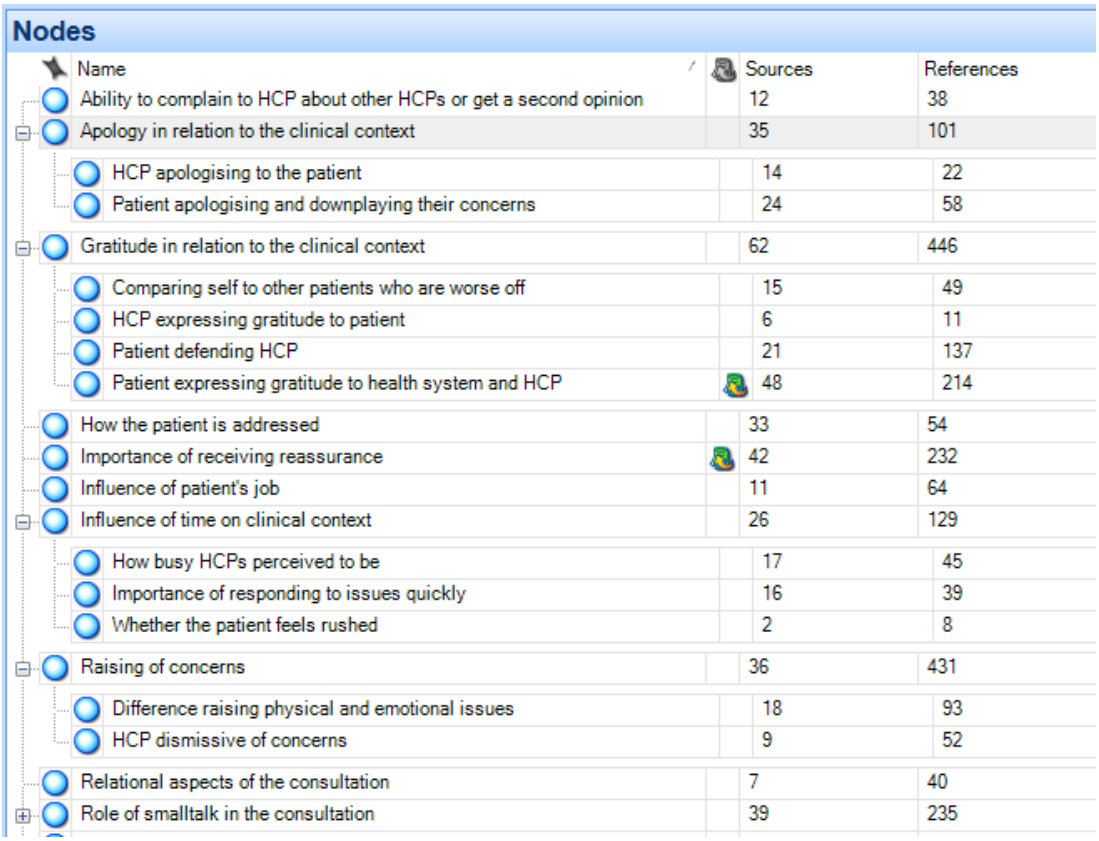
INT You too.

Patient Bye bye.

INT Okay bye.

END OF TAPE

Appendix 11. Example early coding scheme from NVivo



Nodes

Name	Sources	References
Ability to complain to HCP about other HCPs or get a second opinion	12	38
Apology in relation to the clinical context	35	101
HCP apologising to the patient	14	22
Patient apologising and downplaying their concerns	24	58
Gratitude in relation to the clinical context	62	446
Comparing self to other patients who are worse off	15	49
HCP expressing gratitude to patient	6	11
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Patient expressing gratitude to health system and HCP	48	214
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Importance of receiving reassurance	42	232
Influence of patient's job	11	64
Influence of time on clinical context	26	129
How busy HCPs perceived to be	17	45
Importance of responding to issues quickly	16	39
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